PROCEEDINGS
Fourth Annual Conference
of the
Model Reporting Area
for
Blindness Statistics
1965

U.S. DEPARTMENT OF
EALTH, EDUCATION, AND WELFARE
Public Health Service

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Fourth Annual Conference of the Model Reporting Area for Blindness Statistics 1965

Bethesda, Maryland
May 20–21, 1965

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Public Health Service
National Institutes of Health, National Institute of
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PROCEEDINGS OF THE FOURTH ANNUAL CONFERENCE OF THE MODEL REPORTING AREA FOR BLINDNESS STATISTICS

BETHESDA, MARYLAND

MAY 20-21, 1965

I. INTRODUCTION

The Fourth Annual Conference of the Model Reporting Area for Blindness Statistics (MRA), sponsored by the National Institute of Neurological Diseases and Blindness (NINDB),[1] was held on May 20-21, 1965, at the National Institutes of Health, Bethesda, Md. The agenda of the Fourth Annual Conference was concerned principally with progress and development of the MRA, blindness statistics resulting from the MRA program, and selected topics concerned with the definition of blindness, need for socio-economic data on the blind, quality control applied to classification of causes of blindness, and survey of causes of blindness in Canada.

In attendance at the Fourth Annual Conference were the administrators (or designated representatives) from all 12 member States, including the States of New Mexico and Virginia which were formally admitted to the MRA at the Conference, representatives from six nonmember States, and representatives from various Federal agencies, national voluntary and research agencies, and other institutions concerned with the problem of vision improvement. The MRA States represented were Connecticut, Kansas, Louisiana, Massachusetts, New Hampshire, New Jersey, New Mexico, North Carolina, Oregon, Rhode Island, Vermont, and Virginia. Nonmember States represented were District of Columbia, Georgia, Maryland, New York, South Dakota, and Utah. Attending the Conference from national voluntary agencies were representatives of the American Foundation for the Blind and the National Society for the Prevention of Blindness; from national research agencies, representatives from Research to Prevent Blindness and American Institute for Research. Federal agencies with blindness programs which were represented at the Conference included the Library of Congress, Office of Education, Vocational Rehabilitation Administration, Welfare Administration; and the following agencies of the Public Health Service: Office of the Surgeon General, Bureau of State Services, National Institutes of Health, Division of Research Grants, National Institute of Child Health and Human Development, and National Institute of Neurological Diseases and Blindness. There was also a representative from Gallaudet College.

Chairman of the sessions was Dr. Hyman Goldstein, Chief of the Biometrics Branch, National Institute of Neurological Diseases and Blindness.

Dr. William F. Caveness, Associate Director of Collaborative and Field Research of the Institute, in welcoming the participants on behalf of the NINDB, called attention to the acclaim that the efforts of MRA were receiving nationally and internationally. He indicated that the success of the MRA would mean that sound statistics on the magnitude of the problem of blindness would, for the first time, become available. This would provide cogent leads for both administration and research, particularly in uncovering etiological factors, an essential first step in the prevention or alleviation of blindness.

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[1] National Institutes of Health, Public Health Services, U.S. Department of Health, Education, and Welfare.

II. SPECIAL PRESENTATIONS

a. Dr. Milton D. Graham, Director, Department of Research, American Foundation for the Blind, presented a paper on "The Importance of Socio-Economic Data for the Model Reporting Area for Blindness Statistics." (See Appendix A for this paper and discussion which followed.) A summary of this paper appears below.

SUMMARY

Dr. Graham noted that during the five year history (including the planning period) of the Model Reporting Area (MRA) the first of the two major concerns of the MRA, the need for standard definitions for uniform reporting, has basically been fulfilled. However, the second major concern, the need for certain kinds of data on blindness and severe vision impairment, has been only partially realized. Of course, data on required items such as cause of blindness, visual acuity, etc., are being collected but certain highly important socio-economic data remain as only "recommended" items. Dr. Graham reminded the conferees that the importance of certain socio-economic data has been stressed during previous MRA conferences.

He emphasized that at both State and national levels, there is need at least for socio-economic data on blindness and severe vision impairments and, hopefully in time, on less severe vision impairments. Today, as a result of five years research in various problem areas, specific suggestions can be made as to what socio-economic data would be most useful.

Dr. Graham quoted estimates of the incidence and prevalence of blindness in the United States, the number of persons with permanent noncorrectable vision defects, and the number of blind persons unable to read newspaper type even with the aid of glasses. He further quoted a report which indicated that eight out of ten cases of blindness are due to diseases of which the causes are unknown to science. In view of such conditions, it is clear that the cause of increased ophthalmic research has great need for the present MRA data to demonstrate beyond doubt the national need to meet more decisively the challenge of blinding eye diseases. The extension of MRA efforts in collecting selected socio-economic data would facilitate at national and State levels the alleviation, if not the solution, of well-recognized problems that blind and severely visually impaired people meet.

Several recent studies and surveys throughout the country were elaborated on which emphasized the urgent and necessary need for determining: (1) for children: their residence (home, institutionalized, etc.), near vision measurements, and primary mode of reading (sight, braille, etc.); (2) for working-age adults: principal mode of mobility (sight, guide dog, long cane, etc.), income, and residence; and (3) for aged adults: living arrangements (own home, roomer, alone, etc.), income, principal mode of mobility, and other physical impairments.

The types of socio-economic data listed above are only illustrations of data which would be most useful in research and program planning. Before collecting such data, the establishment of standard definitions for uniform reporting would be necessary. Dr. Graham stressed that such problems were not insurmountable in that similar problems have been solved in the past through conferences and workshops.

Dr. Graham concluded on a note of urgency. The number of blind and severely visually impaired persons is increasing and is expected to continue increasing as time goes on, especially since more premature babies who are prone to neurological conditions (including those leading to blindness) are surviving and since the longevity of the population is increasing. Research in blindness needs the necessary statistical base to know where to start, what problems are most pressing, etc. Similarly, the program planners can use such statistics in order to strengthen some programs and initiate others.

b. Dr. Alexander E. MacDonald, Consultant (Ophthalmology), the Canadian National Institute for the Blind, presented a paper in absentia on "Causes of Blindness in Canada: An Analysis of 24,605 Cases Registered with the Canadian National Institute for the Blind." (See Appendix B for this paper.) A summary of the paper appears below.

SUMMARY

Dr. MacDonald reported a survey of blind persons in Canada, based on registrations with the Canadian National Institute for the Blind (CNIB), a voluntary agency. This was the first study of its type having national scope and based on data registered in a central file. Each patient's history was studied by the consulting ophthalmologist who was responsible for the cross-classification of topography (site and type) and etiology (primary cause of blindness). This was a national survey of practically all blind persons in Canada although registration of blindness is not mandatory in that country. It included blind persons of all ages in a punch card file that will be continued indefinitely. The survey covered 24,605 living registered blind persons ranging from premature infants to very elderly persons in 10 provinces and the territories.

Some 51 percent of the cases studied were males and 49 percent, females. The age distribution revealed that about 54 percent were under 65 years of age with 46 percent 65 years and over. Where age at time of registration was known, the greatest number of patients were found to be registered when they were between the ages of 19 and 64. This was true in every major cause category with the exception of macular degeneration (most registered at age 70 years and over) and multiple anomalies (most registered at birth).

Sometimes the onset of the condition preceded by years the time of registration, such as in retinitis pigmentosa, a genetic defect.

In terms of frequency, the principal causes were lesions affecting the globe (e.g., glaucoma, myopia), 36 percent; the retina, 23 percent; the lens, 16 percent; and the optic nerve, 11 percent. In this study, 32 percent of the blindness was due to prenatal causes.

The prevalence of blindness per 100,000 persons in Canada, based on CNIB data was 131, varying among the provinces from 108 to 376 per 100,000 for the North West Territories above the latitude, 60th parallel north.

Serious ocular disease was four times more prevalent than blindness; 101,436 such cases (the "prevention" group) or 539 per 100,000 population, were listed by the CNIB.

III. PROGRESS IN MODEL REPORTING AREA STATES DURING 1964

CONNECTICUT: Mr. McCollam informed the conferees that during the past year Connecticut had adopted the standard eye report form devised by the National Society for the Prevention of Blindness. He felt that the new eye report form was instrumental in getting more and better information from the ophthalmologists throughout the State.

Progress had been made in contacting ophthalmologists by using a feedback system to give them the benefit of the tables derived from Model Reporting Area data. Mr. McCollam felt that the feedback of data provided the referring ophthalmologists with a better understanding of the Model Reporting Area program. Further, the ophthalmologists and eye-ear-nose-and-throat specialists throughout the State had obtained a better understanding of the purposes and goals of the Model Reporting Area through the presentation of a paper relating to the Model Reporting Area by the Connecticut consulting ophthalmologist at a Connecticut Medical Association meeting. Mr. McCollam thought that these efforts stimulated interest in the program among ophthalmologists.

Mr. McCollam indicated that a rather intensive survey had been carried out on the 3,346 persons on the Connecticut register as of January 1964. It was determined that 2,260 persons had been given direct services. Of the balance, some 650 persons were contacted by mail. These persons were asked to check, on a self-addressed, stamped card, whether or not they were still at the same address, if their vision had changed, and if they were in need of any services. Replies were received from 539 persons. The 111 who did not reply were followed up with service calls from members of the Agency staff and eventually a contact was made with all 111 blind persons. Of the remaining 436 visually handicapped persons on their register (these were residents of the larger cities and communities), all but three were contacted through direct calls by the Agency staff. Upon completion of this updating, the register was determined to contain 3,199 persons. Mr. McCollam felt that this was a worthwhile accomplishment inasmuch as the survey was carried out without hiring additional staff.

It was noted that following the survey in Connecticut, a followup procedure for all registrants had been established. In particular, the system was established in order to maintain some contact with individuals who were not in need of services as determined by case workers. According to this system, Mr. McCollam's agency issues follow-up cards to case workers, and it is the responsibility of the last case worker who visited a given registrant to make a contact with that registrant at least once a year, hopefully every six months. Mr. McCollam thought that this could be done once a year. He felt it was a very important procedure for maintaining liaison with registrants regardless of whether or not they were in need of services, and for keeping track of all registrants.

Mr. McCollam mentioned that there were problems in the coding of cause-of-blindness information.

KANSAS: Mr. Hayes reported that in an effort to improve the effectiveness of the Kansas Division of Services for the Blind (DSB) in obtaining and maintaining complete and accurate information for each person carried on the State register of blind persons, an examination was made of practices and procedures in effect. All Division personnel involved in gathering and recording register information were consulted. As a result of this effort, some changes were made which have accelerated the completion of register information and eliminated duplication of effort.

Since the Division of Services of the Blind works in conjunction with the Kansas county Departments of Social Welfare in providing services, the counties have also had a great deal of responsibility for obtaining register information. The counties continued to do so but some modifications of procedures have been made. Currently, Division staff members who are in direct and regular contact with the person registered or to be registered assume primary responsibility for obtaining initial and subsequent register information. Staff members most involved are home teachers and vocational rehabilitation counselors but any others working directly with a client also share responsibility for obtaining register information. All register information obtained by Division staff is subsequently transmitted to the county departments. This is done by several means.

Copies of the narrative dictation of home teachers are sent to the county departments. Register information changes are noted in this dictation and no further notification is given in these cases. Vocational rehabilitation counselors confer with the county department as needed regarding cases. Register information is exchanged during these conferences and on form notices. In addition, the counselors may send copies of selected narrative entries or correspondence which indicate needed revisions to register information. It is the responsibility of the county agency to update the county records. From the central office, notification is by a letter, or on a special "Transmittal Letter" form, from the register clerk. This form is also used to request missing information.

To obtain missing information for persons not being contacted regularly by a member of the DSB staff, the county departments are asked regularly to provide the information through follow-ups at quarterly intervals.

Requests are made and replies received on a "transmittal letter" issued by the register clerk.

Counties also assist in regularly updating register information. Informational changes which should be recorded on the register card are reported on a "Monthly Report of Services to the Blind and Prevention of Blindness," a copy of which is required for each person contacted. Mr. Hayes noted that since the State Department of Social Welfare rules and regulations require at least yearly visits by a county worker to each blind person, a system is in effect which could provide annual evaluation of the need for updating each register card. Steps have been taken to encourage fullest cooperation in this procedure.

The DSB also administers the talking book service as a direct service to the client, but according to Mr. Hayes there is no significant direct contact with the client by DSB staff members. Communication is generally by correspondence. Since the only eligibility for talking book services is proof of legal blindness, Mr. Hayes indicated that in the past complete register information has not always been obtained, especially when talking book service has been the only service provided to the registrant. The problem seems to have been solved through use of an application form which requests but does not require complete register information. Cooperation of applicants has been excellent, according to Mr. Hayes, and none have refused to provide the information voluntarily. Some application blanks have been mailed directly to the applicant and some to the county welfare departments with a request to obtain the desired information from the applicants.

It was emphasized that another significant help in getting complete, accurate, and current eye information is the policy which enables the State Department of Social Welfare to pay for eye information or eye examinations for those persons who are unable to pay for them. For eligible persons, travel and maintenance expense incurred in obtaining an eye examination may also be paid. There is no formal means test for payment of eye examination, and authorization for payment is made by county welfare directors. Approval for payment is contingent upon the eye report being submitted on the DSB form by the ophthalmologist. In addition, a social report containing all other essential eye information is required.

Mr. Hayes felt that the DSB was getting better reporting from the eye physicians, probably a partial result of the fact that the DSB is maintaining a fairly close contact with them. As an aid in this contact, the statistics derived from the Model Reporting Area are being sent to medical eye specialists for their review.

According to Mr. Hayes, the Kansas State supervising ophthalmologist and other physicians in the State were pleased with the coding improvement in the cause-of-blindness classification and with the new eye examination report form designed by the National Society for the Prevention of Blindness which the DSB recently adopted.

Mr. Hayes believed that perhaps the greatest need appears to be in devising ways and means of reaching the eye physician to insure reporting of all blindness regardless of the service needs. A medical advisory committee which has recently been reactivated should be of great help with this. Also, the DSB plans to report to the eye physicians annually or semi-annually on program activities. This was initiated in order to keep each physician alerted to the importance of registering blind persons and to stimulate his interest in this activity.

LOUISIANA: According to Miss Ford, approximately 4,200 of the 6,200 blind registrants during the past year received some service from the Department of Public Welfare (DPW) and thus did not have to be contacted further for the annual clearance. The remaining registrants were contacted by mail and asked to return a self-addressed, stamped card on which was to be noted any change in name, address, or vision during the preceding year, or whether the registrant was interested in any service offered by the

Division of Public Welfare. Approximately one-third of the registrants replied. The DPW sent a return letter to these registrants thanking them for their reply and advising them of its plan and whether or not the DPW could be of assistance. Miss Ford noted that in most instances the DPW could do little regarding services because the particular group replying, for the most part, were either not welfare recipients or no longer required services. Although they received service in the past many of these respondents were totally blind.

The names of those registrants not answering the first mailing, were given to case workers on an area basis with a request that the case worker follow up on those registrants. Those registrants who were not located by the case worker were removed from the "active" register; however, the DPW would continue to make all possible efforts to locate the registrants. Persons determined to have died or recovered vision were also removed from the register.

Miss Ford indicated that the DPW was hopeful of initiating a newsletter pertaining to topics of interest for blind persons to be sent to each registrant. The purposes of the newsletter would be twofold. That is, the letter would inform blind persons of items of interest to them, and would act as a means of contacting the registrants since a quotation at the bottom of the newsletter would ask the registrant to write to the DPW advising it of the registrant's feeling about the letter. Miss Ford believed that the newsletter could be an important means of contacting persons who were not in need of services.

Miss Ford noted that Louisiana would begin as soon as possible to recode its entire register according to the 1965 revision of the Standard Classification of Causes of Severe Vision Impairment and Blindness. The State supervising ophthalmologist plans to recode according to etiology, thereby eliminating delays inherent in skipping back and forth through the Classification.

It is planned to make extensive contacts with the practicing ophthalmologists in the State. The MRA annual statistical reports will be made available to these physicians as part of this plan, and the consultant ophthalmologist may present a paper on their program at the annual meeting of the State ophthalmologists.

In Louisiana, some 1,600 registrants receive talking book machines on loan. Approximately six to eight hundred of the borrowers are not public assistance recipients and, therefore, no eye reports are available for them. In order to receive a talking book machine only a "certificate of blindness" is necessary from an ophthalmologist or optometrist. According to Miss Ford, some doctors will record etiology, visual acuity, and other items, while others will only give visual acuity since the Library of Congress only requires a statement from the doctor that the applicant is legally blind. Miss Ford did not believe that the DPW would ever get eye reports on all talking book machine recipients; however, the DPW has revised its "certificate of blindness" (that is, application for the talking book machine) to indicate that for the form to be valid, it must be completed, in total, by an eye physician or optometrist.

MASSACHUSETTS: In the past year the Massachusetts Division of the Blind was able to update its register with regard to information on race which, until then, had been impossible to do. Mr. Mungovan stated that because the nonwhite population of Massachusetts is less than three percent, and since race made no difference in the kind of services rendered, the Division did not record the race of registrants on its statistical card. Hence, in previous years the Division's figures have shown a very large number of "unknown race" in the tabulations by race. The statistical cards have been completed and future tabulations will show very few persons to be of unknown race.

Also in previous tabulations, Massachusetts has shown a large number of "unknowns" in the discipline of examiner entry. Through a special effort to transfer discipline of examiner data from the Division's records to its McBee keysort punch cards, this problem was resolved. It was determined that some 821 of the 947 first additions to the register during 1964 were examined by ophthalmologists or eye-ear-nose-and-throat specialists, and only 25 were of unknown discipline. Mr. Mungovan stated that the Division is contemplating putting its register data on IBM punch cards. However, it did not appear likely that an appropriation for this purpose would be granted during the fiscal year 1966. He noted that the Division's biggest problem was not the counting of statistical cards but the recording of data and the transfer of information known to the field staff to the Division's statistical system. The Division's lack of adequate social work staff in proportion to the demands for service required the Division to place the greatest effort in supporting the field staff and holding statistical and research work to a minimum.

During the past year, the Division has established a system for the destruction of closed case records. All inactive case records up to 1963 were microfilmed and destroyed. With the microfilming, the Division has set up an IBM index card which will be interfiled alphabetically so that the index to all closed cases will be printed from a computer into a book about the size of a telephone book. Mr. Mungovan said that the IBM cards will be retained so that the Division will be able annually to microfilm closed records and establish a new, completely alphabetical index. Retrieval of old records will be possible through the use of this updated alphabetical index and the revival, if necessary, of a record from the microfilm using a reader-printer machine. The IBM card used for indexing the microfilm record will have sufficient space available to enter Model Reporting Area data if the Division gets to the point of punching its own statistical cards in the Division of the Blind.

Mr. Mungovan outlined some of the problems with which the Division deals. Specifically, the Division has tried to improve the quality of data on incidence and prevalence of blindness and to more accurately classify site and type of affection and etiology. Also, the Division has attempted for many years to arrive at data on onset of blindness without much success. Mr. Mungovan felt that data on date of onset probably should be sought through special studies on a sampling basis. Further, Mr. Mungovan was of the opinion that studies should be conducted to determine how many blind persons are not on registers even in States which have mandatory reporting laws. To his knowledge, no such studies have ever been done. He pointed out that physicians, clinics, and optometrists report blindness almost exclusively after a judgment as to what the agencies can do for the person who has become blind, rather than due to a law which requires them to report blindness. Mr. Mungovan recommended that, among other ways, such a study could be done by examining the records of elderly recipients of Old Age Assistance or Medical Assistance to the Aged. He thought it would be desirable and interesting to know just how complete the blindness registers are.

Still another area needing investigation was the possible development of deafness and blindness in children due to a recent outbreak of rubella. Mr. Mungovan noted that in Massachusetts they were beginning to observe an increase in reported blindness in babies and he wondered if this was a reflection of the effect of rubella in pregnant women. However, he said that this increase was not as high as during the peak of retrolental fibroplasia affections. He felt that the problem should be examined closely to see if it warranted special effort in the immediate future. If it is found that this cause of blindness among children will increase significantly, plans should be made to develop special educational programs for these children. He noted that the combined defect of hearing loss and vision impairment was of particular concern in this regard.

NEW HAMPSHIRE: Mr. Camp indicated that although the New Hampshire register of blind persons is a small one, it has the same types of problems which appear to exist in the other MRA States. These are being resolved with the aid of the Biometrics Branch staff. Also, with assistance from the NINDB, the Services to the Blind was beginning a revision of its register onto a punch card system. This will involve the updating of its register, including the coding of the causes of blindness for the entire register.

Mr. Camp felt that New Hampshire was progressing towards the goals of the MRA; and he was hopeful of contributing to the program despite the fact that New Hampshire had a relatively small register.

NEW JERSEY: During the past year the registrar for the New Jersey Commission for the Blind attended the coding conference on causes of blindness held in Bethesda, the beneficial results of which are reflected in New Jersey's statistics according to Mr. Kohn. He noted that New Jersey had been actively participating in the attempt at uniform coding and was very interested in the subject.

The Commission recently appointed a committee for data processing made up of professional staff members within the Commission. The Committee will consult with the various departments of the Commission in order to determine the need for further development and expansion of the types of information on blindness to be collected and coded. In connection with this, certain tabulations were made by degree of vision, age, county of residence, age at onset, and source of referral for new additions to the register and end-of-year total on the register, as well as tables on closures and total case load (i.e., end-of-year total plus closures). The tables were transmitted to the Commission's professional staff for their knowledge and use, particularly in public presentations, so that each staff member would be giving out uniform and correct information.

It is interesting to note that during New Jersey's first year in the Model Reporting Area, the total number of blind persons on the register decreased from the previous year due to updating procedures initiated in compliance with Model Reporting Area standards. In each succeeding year there has been a net increase in the total number of blind persons on the register to the point that Mr. Kohn estimated for 1965 there would be a net increase of approximately 500 blind persons on the register.

The Commission is in the process of trying to obtain a medical director on a part-time basis, in addition to the ophthalmological and medical consultant already working with the Commission. The need for a medical director is particularly acute in view of the fact that, as estimated by Mr. Kohn, a minimum of 40 percent of blind persons on the register are multiply handicapped. Except for hearing loss and diabetes among the multiply handicapped blind, there did not seem to be a preponderance of any one specific additional handicap.

NEW MEXICO: The register in New Mexico actually was an outgrowth of a bill for an orientation center which was considered by the State Legislature two years ago. The Legislature decided that an interim study should be made to determine the need for an orientation center and it was this which stimulated interest in a complete blindness register. Such a register was eventually achieved with the aid of the Biometrics Branch, NINDB, which brought New Mexico into the MRA.

The chief problems in New Mexico are the lack of necessary personnel in addition to the fact that the relatively small population in New Mexico is scattered over a large area. Mr. Hebbeln indicated that the State Legislature had set aside recommendations for hiring more personnel for the blindness agency. However, he hoped that expansion of the agency would take place over a period of time. The blindness agency had expanded its rehabilitation activities and had begun several other services for blind persons.

Mr. Hebbeln noted that New Mexico received good cooperation from its ophthalmologists; however, some of the ophthalmologists tend to refer blind persons via letter rather than eye reports. This had caused some problems for the supervising ophthalmologist in determining the extent of blindness. He stated, also, that the current Legislature was considering a bill dealing with whether a public agency employee can indicate to his client who should examine his eyes.

The blindness register makes use of a

Remington Rand data processing system within the State Department of Welfare. Mr. Hebbeln noted that recently there were indications that a central data processing system for the various State departments might be developed. Mr. Hebbeln felt that such a system would facilitate the obtaining of tabulations needed by the blindness agency.

NORTH CAROLINA: A continuous updating and referral system has been established in North Carolina whereby the county welfare departments play a greater role than has been the case in the past. Miss Anderson felt that this would expedite the reporting of information from the local level. To facilitate this procedure the North Carolina State Commission for the Blind returns to each county the duplicates of the register cards of persons residing in the specific counties.

Feedback of Model Reporting Area data has been a major part of the Commission's activity during the past year. Such information is sent not only to ophthalmologists and eye-ear-nose-and-throat specialists, but to the public health and public welfare departments as well. Also, the Commission, in its biennial report, publishes the number of blind people in each county by race, sex, age, and age at onset of blindness, which in turn is a source of information to the counties. As part of its ongoing educational program, the Commission sends representatives to workshops which are held throughout the State and are conducted by the Lions Clubs. At the workshops, the representatives explain the purpose of and services offered by the Commission for the Blind, as well as the Commission's future plans.

One of the present activities of the Commission is to encourage the medical eye specialists in the State to use the new medical eye report forms which have been distributed to them. Apparently, the ophthalmologists in the State still have a supply of old eye report forms and, through force of habit, are continuing to use them.

There are still some problems in coding of causes of blindness partly due to the use by some ophthalmologists of the old eye report form which was not designed for obtaining detailed information on cause of blindness. However, the registrar is giving much effort and study to this activity, including the taking of a correspondence course and reading various books on the subject.

The Commission's plans for cooperating in certain research projects in the near future include work with preschool children, mentally retarded blind children, and children at the State School for the Blind. Also, the Commission is cooperating with the State mental hospitals in a study to determine the effects of new drugs on severely disturbed psychiatric patients, and specifically the ophthalmological side effects of the drugs on the patients. The Commission is continuing its research activities on its glaucoma cases, the purpose of which is to study the variation and the incidence of glaucoma according to such factors as sex, race, age, and geographic locality.

Miss Anderson indicated that during the past year major emphasis has been placed on a sharpening of procedures for data collection, particularly in reference to the socioeconomic data. She also noted that the Commission requires eye examination reports and has no problem in obtaining them on private patients who are seeking any service.

OREGON: Although the Oregon State Commission for the Blind has been authorized to maintain a register of the blind since 1937, only since the initiation of the Model Reporting Area program in Oregon have valid statistics on blind persons been maintained.

To maintain the register on an up-to-date basis, Mr. Stocker indicated that the Commission had initiated its first annual updating procedures in the fall of 1964 and this was completed by the end of the year. The library which dispenses talking book machines and records is used as a first check since approximately 65 percent of blind persons in Oregon are talking book users. Next, the welfare records are checked. This procedure has been modified since the Welfare Department sends monthly to the Commission a list of all Aid to the Blind applicants in addition to those persons removed from the

Aid to the Blind program and this information is used in keeping the register current. Additional information is received from the outpatient clinic at the University of Oregon Medical School on persons with severe vision impairment, and eye reports are received on everyone enrolled at the School for the Blind. Arrangements are made by either the Commission for the Blind or the School for the Blind to obtain eye examinations on persons enrolled at the School for the Blind who do not have current eye reports. A letter is sent to those persons on the register for whom there has been no contact in order to verify the fact that they are still legally blind and living in Oregon. A personal contact is attempted by Commission personnel for those persons not answering the inquiry.

Mr. Stocker emphasized that the Commission has good working relations with the ophthalmologists in Oregon. The Commission pays $3.00 for a copy of a medical report and $15.00 for an eye examination with all required information included on the examination report. Ophthalmologists in the State are being urged to report to the Commission any changes in status of their blind patients in order that corresponding changes can be made in the register data.

Mr. Stocker noted that physicians in Oregon, in addition to ophthalmologists, have shown interest in statistics derived from the Model Reporting Area. Therefore, at least a condensed version of the annual tabulations might be distributed in the near future to the entire membership of the Oregon State Medical Society. The State Legislature has also shown an interest in the blindness statistics.

Mr. Stocker pointed out that the problem of personnel shortages in the Model Reporting Area States could be alleviated somewhat through the use of high school students connected with the National Youth Corps program as is being done in Oregon. The Oregon State Commission for the Blind is using two such students for filing, recording of information, etc., thereby freeing a portion of the professional staff's time for other important duties. Apparently, the students are not only doing a good job but are being indoctrinated so that, in time, they might be hired by the Commission on a full time basis to replace retirees.

Mr. Stocker mentioned that, thus far, he has found a well maintained blindness register to be highly beneficial.

RHODE ISLAND: During the past year the Rhode Island Division of Services for the Blind has further streamlined its MRA reporting procedure within the agency. A system has been established whereby data for coding is gathered during each monthly ophthalmological consultation and this information, in turn, is submitted to the MRA coordinator within the following week for further IBM processing.

The Division has also simplified its master register by reducing the number of filing sections from four to three. There is now one "closed" file for both MRA and non-MRA cases, one "MRA active" file and one "pending non-MRA" file. In conjunction with the register is the development of a master index file which contains names, addresses, etc., of all persons known to the Division and the location of their register cards within the MRA register. This addition creates a valuable tool for rapid assessment and location for each person.

Services by the Division were interrupted this year due to turnover of personnel. Therefore, full utilization of the tables for further research was impossible. However, the Division's personnel are now more familiar with the coding process and the Division's internal schedules have been working out more smoothly.

Miss DeTommaso noted that the research office in the Rhode Island Department of Social Welfare, while it is overburdened, feels that the preparation of tables is the rewarding part of data collection. Therefore, the research office welcomes the opportunity to provide certain basic tables required by the Division of Services for the Blind, particularly since the preparation of such tables helps new research staff to understand the IBM machine capabilities. Miss DeTommaso stressed that although time has permitted only a brief discussion between the research unit and the Administrator of Services for the Blind concerning the current tabulations, a more productive meeting in the near future should help to bring about an understanding of the characteristics and attributes of the patients served at the agency with the ultimate objective of improving the Division's services. Additional tabulations will be made to meet the needs of the Division, particularly as they relate to the total register.

Miss DeTommaso indicated that the section on field of vision in the eye report form had been revised in order to motivate physicians to complete that vital section of the eye report form.

The coders in the Division feel that the Quality Control Program on cause of blindness will help improve the validity and reliability of such data. However, it is hoped that the problem of time-consuming corrections will be reduced soon once the Standard Classification becomes fixed and firmly entrenched.

According to Miss DeTommaso, the effects of the MRA continue to permeate the individual services rendered by the Division. Intake procedures, medical diagnostics, case load management, case work planning, etc., are but a few of the areas in which the MRA has played a valuable role in the improvement of program quality.

VERMONT: Miss Cole reported that Vermont was pleased to find that there were some real bonuses attached to a good register. In Vermont there is now a smooth flow of procedures related to the intake of the referrals. A new referral control book has been established whereby a new referral can be followed until assigned to a case worker and registered. The book serves as a chronological record of all new referrals and is used as a check for followup needs. The register log book has a function beyond that of just assigning case numbers. For example, at any given point in time personnel of Services for the Blind can make a tally of blind persons added to the register and those removed from the register and reason for removal.

During the past year Vermont has integrated alphabetically the register cards and eye reports of both the persons determined to be legally blind and those still pending, thereby eliminating considerable time it would otherwise take in trying to determine the client's status before being able to pull the card and eye report. Therefore, the emphasis is placed upon individuals being served rather than upon whether or not they have become registered. Further, the file has become a valuable instrument in facilitating weekly case conferences and in keeping progress notes and records of services. At the case conferences the cards are updated for changes of address, new eye exams, etc., and new information which is learned through field visits.

Miss Cole noted that her agency has adopted, without any problem, the NSPB eye examination report form which is recommended by the MRA.

Updating of the register is kept fairly current through the use of a newspaper published by the Vermont Services for the Blind on alternate months and sent to the blind registrants. Miss Cole thought this was one of the best ways of keeping in touch with registrants. Twice a year the paper is sent first class mail so that postmasters, relatives, and boarding and nursing home administrators return the letters if recipients are deceased. When a newspaper is returned as "unable to locate," relocation is assigned to a field worker. Also, daily papers are scanned for obituaries. The Public Assistance monthly control book is used each month for checking deceased Old Age Assistance recipients. Miss Cole indicated that punching the register IBM cards is done by Services for the Blind personnel. Also, because of the small number of cards involved, the sorting of the cards is often done by hand to obtain certain data, rather than waiting to fit the work into the machine schedule.

The data processing unit each year furnishes a current listing of the register data from which Miss Cole's staff prepares a digest of the data which, in turn, is released to ophthalmologists and optometrists throughout the State. This has been one of the truly beneficial aspects of the punch card system. Miss Cole emphasized the importance of preparing the data in digest form for distribution to ophthalmologists and optometrists. The data will be looked at more carefully by those practitioners if it is presented in a concise manner.

Miss Cole believed there is an increased awareness on the part of the medical eye specialists for accurate reporting. However, Miss Cole felt that a significant problem was the lack of time she had for personal contact with the physicians relating to their patients who are also clients of the Services to the Blind, and to explain to the physicians the Services for the Blind's involvement in the Model Reporting Area for Blindness Statistics.

VIRGINIA: During the past year Virginia spent much of its time revising and updating its register which enabled it to become a member of the Model Reporting Area for Blindness Statistics.

Mr. Coppage mentioned that during the year several sessions to provide in-service training and experience for clerical personnel, one from each of the various services such as Aid to the Blind, Vocational Rehabilitation, Home Teaching, etc., were held. These persons have the responsibility of becoming familiar with the forms and procedures so that the information which is sent to the registrar will be as complete as possible and will be done with as little delay as possible. The statistics derived from the updated register will be contained in the Commission's annual report.

It was noted by Mr. Coppage that the problems in Virginia, specifically that of getting complete referrals, are similar to those discussed in the presentations of other Model Reporting Area States.

IV. PROGRESS IN SELECTED NON-MODEL REPORTING AREA STATES DURING 1964

DISTRICT OF COLUMBIA: Mr. Gambaro informed the conferees that until one year ago the District of Columbia had no register of blind persons. The Division of Services to the Visually Impaired is now establishing such a register and presently has 1,900 unduplicated names of visually impaired persons out of a projected estimate of 3,000 such persons. Mr. Gambaro indicated that the 1,900 names had been obtained from other agencies serving visually impaired persons in the District of Columbia. He felt that the names of an additional 1,100 visually impaired persons who have not been registered would be obtained from the files of medical eye specialists in the District of Columbia.

Mr. Gambaro indicated that agencies serving blind persons in the District of Columbia initially were hesitant to cooperate with a register of blind persons for fear that rapport among agencies and their clients would be destroyed. However, Mr. Gambaro was pleased to report that the agencies were now cooperating fully since they were assured that the Division of Services for the Visually Impaired would contact all the referral sources for missing information rather than making direct contacts with the visually impaired persons. In cooperation with the other agencies the Division is going to try to procure eye reports on all persons on the register. Mr. Gambaro stressed that it is the Division's desire to cooperate with the other agencies in making the register of visually impaired persons a case-finding tool as well as a research tool.

Although the Division has obtained funds for a registrar, etc., and therefore, official recognition of the register from the Congress, a register law and a mandatory reporting law has not yet been passed by the Congress. Mr. Gambaro felt that a mandatory reporting law was important because it would protect referral sources from breach-of-confidentiality suits. He also believed that a mandatory reporting law would help keep the register current by having information reported to the Division on a regular basis.

The Division has received an endorsement from the section on ophthalmology of the District of Columbia Medical Society and is getting its full support.

One of the major problems Mr. Gambaro had encountered was the number of visually impaired persons with either no eye report or an incomplete eye report. Mr. Leatherwood noted that in some cases the eye reports were nothing more than a written letter indicating a person was legally blind. He stressed that problems of coding cause of blindness were further compounded by the fact that the District of Columbia has had no standard eye report form; hence much searching has been required in order to obtain essential items such as exact visual acuity, discipline of examiner and cause of blindness.

GEORGIA: Mr. Gaines informed the conferees that, like the District of Columbia, Georgia is in the process of developing a register of blind persons. In the early stages of work towards developing a register, a great deal of effort was made to obtain support of the idea from various agencies interested in blindness. Prior to the actual work on developing the register itself, a law was passed by the Georgia Legislature requiring the Georgia Department of Education, and specifically the Services for the Blind in the Division of Vocational Rehabilitation, to maintain a register of blind persons. Mr. Gaines and other members of the Department of Education have felt that the reporting of blindness on a voluntary basis was the better method for obtaining referrals of blind persons. Therefore, the passage of a mandatory reporting law was not attempted.

The development of the register in Georgia is rather unique in that it is a cooperative effort between the Georgia Division of Rehabilitation and the Community Services for the Blind, Inc., a private agency of prominent Atlanta citizens. After the register has been established it will be the Division of Rehabilitation's responsibility to maintain and keep the register on an up-to-date basis.

Mr. Gaines pointed out that he and members of the Services for the Blind had met with the Georgia Ophthalmological Society to acquaint its members with the purposes and objectives of the register. A committee of ophthalmologists has been appointed to work with the register in developing a system of voluntary reporting which, in fact, seems to be developing successfully. In connection with this, a letter requesting the cooperation and support of ophthalmologists, signed by the chairman of the ophthalmological committee, has been sent to all ophthalmologists in the State.

At the present time the files of the public and private agencies serving blind persons are being reviewed to obtain all medical, social and case-history information available on visually handicapped persons. Thus far complete information has been obtained for approximately 5,000 blind persons.

Excellent cooperation and support has been obtained from the public and private agencies in the State which provide services for blind persons, thereby assuring referral of such persons to the register. All possible sources of referral in the State will be contacted in developing the register, including convalescent homes and State mental institutions. Rapport with all such agencies will be maintained to assure a continuously accurate register.

Mr. Gaines mentioned that Services for the Blind had developed a pamphlet containing information as to why a register of blind persons is being developed and ways in which it will be used. The pamphlet has been sent to all agencies and ophthalmologists in Georgia.

Finally, Mr. Gaines noted that a registrar has been obtained and work on the register is progressing rapidly towards eventual MRA membership.

NEW YORK: Mr. Friedensohn pointed out that there has been a register of blind persons in New York State since the establishment of the Commission for the Blind in 1913. Work is now under way to revise and update the register of blind persons so that New York might become a member of the Model Reporting Area. Mr. Friedensohn noted that the register was maintained on an up-to-date basis until 1960 when the Commission, for fiscal, procedural, and other reasons, ceased updating its register. He felt that had the Model Reporting Area begun one year earlier, the State of New York would have continued to update its register.

Mr. Friedensohn discussed some of the problems which had to be resolved before administrative approval was given by the State

Department of Welfare (in which the Commission is organizationally located) to maintain an updated register. This approval enabled the Commission to obtain the assistance of NINDB, under contract, to bring its current register up to date and work towards MRA membership. In this connection, Mr. Friedensohn commented on recent events which demonstrated the desirability and necessity for maintaining an up-to-date register of blind persons. He noted that the Commission was asked by the Governor of the State to submit budget estimates for the next 20 years based on the estimated blind population over that same period of time.

After initiating the contract with NINDB a number of problems had to be overcome, including turnover of key personnel and in hiring appropriate people for the project under the State civil service requirements. Also, certain revisions were made in the Commission's records to make them compatible with the MRA system, and this involved revision of forms to include MRA required items.

It is estimated that there are 35,000 blind people in New York State. The existence and whereabouts of approximately half of this number are known to the Commission for the Blind. For example, about 11,000 talking book machines are being used, there are about 2,000 blind persons on the vocational rehabilitation case load, and there are about 2,000 blind children and 3,000 adults who are seen regularly by Commission personnel. According to Mr. Friedensohn, the one area in which the Commission does not have good data available is in the public assistance programs. Less than two percent of the blind people in New York receive Aid to the Blind while other blind persons who are in need of financial assistance are referred to other public assistance programs such as Old Age Assistance. In New York State the budgetary grant and administration of public assistance programs are the same regardless of type of program. It was Mr. Friedensohn's opinion that the local welfare districts may, for various reasons, put blind persons on assistance programs other than Aid to the Blind and this would obviate the necessity of clearance with the Commission regarding blindness confirmation as is done with the Aid to the Blind applicants. Thus, some blind persons on public assistance may not come to the Commission's attention. Also there are approximately fifteen voluntary agencies throughout the State which provide direct services to certain blind persons. The Commission will institute procedures whereby it will obtain information on current status of such persons.

The Commission is able to secure an ophthalmological eye report on all of its registrants since State law requires that the determination of legal blindness must be made from an ophthalmological report. This is incorporated into the definition of legal blindness and has been in effect since 1945 when reporting of blindness became mandatory. Mr. Friedensohn indicated, however, that this year the Optometric Association will introduce proposed legislation to change the definition of blindness in New York State so that the determination of legal blindness may be made from an optometric report.

Mr. Friedensohn inquired as to how the other States represented at the Conference felt about the need for a full-time, or even part-time, ophthalmological consultant on staff. Consideration is being given to having such a person on staff due to the volume of eye reports in New York.

Mrs. Lawlor commented that the Quality Control Program (on causes of blindness) developed during the past year had been extremely helpful in getting Commission personnel to review and evaluate more closely the eye reports and specifically the cause of blindness information.

SOUTH DAKOTA: Mrs. Flora mentioned that South Dakota was progressing quite well on its register revision and she indicated that approximately 1,200 blind persons of the estimated 1,500 in the State had been registered, register cards completed, and IBM cards punched. Mrs. Flora estimated that there would be from 100 to 150 new additions to the MRA register each year.

She noted that when a person is referred to the Services to the Blind and Visually Handicapped, he is put on a referral basis until either activated or closed and, furthermore, cannot be activated until all the required MRA information has been obtained. Since the Services to the Blind and Visually Handicapped is primarily a rehabilitation agency, the rehabilitation counsellors are charged with the responsibility of obtaining the required MRA information on all persons living within the areas served by the respective counsellors.

Mrs. Flora indicated that the blindness agency had good cooperation with the State and county public welfare departments. All applicants for Aid to the Blind from the Welfare Department must be approved by the Services to the Blind and Visually Handicapped's consulting ophthalmologist. The School for the Blind has also been quite cooperative in that they give the blindness agency continuous updated material on all of its students. Mrs. Flora pointed out that information relating to blindness from the Public Health Service Hospital in South Dakota must be accepted from physicians who may not be eye specialists since that hospital has no ophthalmologist on its staff.

UTAH: Dr. Hall indicated that Utah was continuing the updating of its register so as to become a member of the Model Reporting Area and, although the job has not been finished, much progress has been made. He noted that perhaps the greatest progress made during the past year was the education that has taken place among personnel in the blindness agency concerning the procedures for obtaining and maintaining a good register of blind persons. The register of blind persons in Utah which has been in existence for some years had deteriorated over the past few years. However, this trend has been reversed during the last year.

Another of the major accomplishments during the last year was the passage by the State Legislature of a budget which would maintain the position of registrar, provide money to employ a social worker on the central intake system, provide funds for securing some medical examinations on the backlog of the register as well as medical examination on new referrals and, in general, provide sufficient funds to maintain a register on an up-to-date basis. The blindness agency has also worked closely with, and received cooperation of, the data processing unit in designing the punch card system, etc.

One of the problems in Utah, according to Dr. Hall, was the lack of adequate medical information on about 40 percent of the registrants. The securing of such medical information is difficult since Utah is basically a rural State and, consequently, many blind persons living in rural areas do not have ophthalmological care nearby.

V. ACTIVITIES RELATING TO VISION IMPAIRMENT PERFORMED BY THE BIOMETRICS BRANCH, NATIONAL INSTITUTE OF NEUROLOGICAL DISEASES AND BLINDNESS, DURING 1964

a. ASSISTANCE TO STATES AND OTHER ACTIVITIES RELATING TO THE MODEL REPORTING AREA

Irving D. Goldberg, Assistant Chief,
Biometrics Branch, NINDB.

Mr. Goldberg summarized the activities of the Biometrics Branch related to the Model Reporting Area, including the technical and contractual assistance provided to member and nonmember States, workshop activities, procedures developed for production of MRA statistics, and publications during the year.

With regard to Model Reporting Area States, visits were made to each State to instruct them on procedures for preparing punch cards which were to be submitted to the Biometrics Branch for preparation of the 1964 Statistical Report of the MRA. Those States which do not have punch cards were instructed on procedures for preparation of the required tabulations. On these and other visits to several of the States and through correspondence, other matters of mutual interest to the MRA and the States were discussed. Guidance was provided and problems resolved. Mr. Goldberg noted that a member of the Biometrics Branch staff spoke before employees of one of the member agencies, describing the scope and purpose of the MRA program to that agency's staff. With respect to contractual assistance to MRA States, Mr. Goldberg stated that a contract was initiated with one member State (Oregon) to convert its register to a punch card system, and that a similar contract was in process of initiation with a second member State (New Hampshire). He pointed out that with completion of these two contracts all but one State (Massachusetts) in the MRA program will have its register on a mechanized punch card system. Guidance was provided by the Biometrics staff to the two newly admitted members to the MRA (New Mexico and Virginia), enabling them to complete the registers under contract in accordance with MRA standards.

With reference to nonmember States, Mr. Goldberg mentioned that visits by the Biometrics Branch staff were made to five such States in connection with contracts to revise or develop registers of the blind so as to meet the requirements of the Model Reporting Area. It was expected that for four of the States (District of Columbia, Georgia, South Dakota, and Utah) the contracts would be successfully completed by the end of 1965 or shortly thereafter. The fifth State (New York) had just recently had its contract initiated and it was hoped that this contract would be successfully completed before the next annual conference. Mr. Goldberg noted that the inclusion of these five States in the Model Reporting Area within the next year or so will bring its total membership to 17 States, representing almost one-third of the U.S. population.

The Biometrics Branch was also in communication with other nonmember States and two of these States, Maryland and Oklahoma, which have expressed an interest in the Model Reporting Area program, were visited. Seven other States have directly or indirectly expressed an interest in the MRA program, including California, Montana, Ohio, Pennsylvania, Tennessee, Texas, and Wyoming. With the exception of Texas, there were no significant developments to report regarding those contracts. Mr. Goldberg referred to the report made by the Texas Legislative Council to the 59th Legislature of Texas. From that report he read some of the recommendations of the Council's Study Committee on Services for and Rehabilitation of the Blind. These recommendations included participation of Texas in the MRA program. With reference to the Texas Commission for the Blind, the Committee also recommended in very specific terms the need for adequate staffing at the clerical and higher staff level positions in order to accomplish improvement in the completeness and accuracy of the Texas register. It also recommended that the language of the current statute, which makes the maintenance of the register permissive in nature, be amended and clarified so as to make the maintenance of a register of legally blind persons a requirement of the Commission. Further, it recommended that the register be kept current.

With regard to the mechanization of the MRA program, Mr. Goldberg again noted that all but one State had their registers on punch cards, and it was hoped that that State (Massachusetts) would soon be able to convert its register to a machine system. As a result of this mechanization, and because of the basic uniformity in the register systems with regard to the requirements of the MRA, the punch cards have given a great deal of flexibility to the production of MRA tabulations for routine reports as well as for technical papers (e.g., on the causes of blindness) and for purposes of research. The past year was the first time in which the States sent to the Biometrics Branch punch cards according to specified directions, enabling the Biometrics Branch to prepare the annual tabulations mechanically through computer and other machine facilities. Although it was necessary for the States to edit and prepare their punch cards in suitable form, they were relieved of the necessity for preparing required tabulations themselves. In preparing the data for the annual report the Biometrics Branch was also able to produce machine tabulations for each of the States and such tabulations were sent to the States prior to the Conference. Procedures in this first year of centralized machine processing for MRA tabulations have proved so successful that they resulted in a financial saving, as well as a time saving, in the preparation of the annual MRA Statistical Report. The cooperation of the various States in the editing of the punch cards, so as to minimize the number of errors which had to be queried, and submitting the punch cards to the Biometrics Branch on schedule have greatly contributed to this success.

Another Biometrics Branch activity mentioned by Mr. Goldberg was the Workshop on Coding of Causes of Blindness, sponsored by the Biometrics Branch with the cooperation of the National Society for the Prevention of Blindness, held in February 1965. Coders of causes of blindness in the 17 member and nonmember States participating in the program attended the Conference for training in the use of the 1965 revision of the Standard Classification. Mr. Goldberg noted that growing out of the agreement at the last annual Conference and the Workshop mentioned above was the adoption of a Quality Control Program. This program attempts to achieve the maximum in uniformity throughout the MRA in coding of causes of blindness. He stated that all 17 States are fully cooperating in this program and indicated that Mrs. Moorhead would have more to say about the Quality Control Program later in the Conference.

Mr. Goldberg concluded his report with mention of various papers and materials in the field of blindness which were published or prepared for publication by the Biometrics Branch during the year. These included the following:

1. Proceedings of the Third Annual Conference of the MRA.
2. The Annual MRA Statistical Report for 1963 which was in process of being printed.
3. A paper, "Reported Incidence of Blindness in Selected States in 1962," published in Public Health Reports in 1964.
4. A paper, "Reported Incidence of Blindness by Cause in 1963," published in the Sight-Saving Review, Winter issue, 1964.
5. A paper by Dr. Goldstein, "So That All May See," published in The New Outlook for the Blind in 1964.
6. A paper, "Survivorship and Causes of Death Among the Blind," based on the Massachusetts register, to be published in the Journal of Chronic Diseases.
7. Analysis being completed on a study to be published on the etiology of blindness in children based on the New York State register.
8. A paper being prepared for publication on the reported incidence of blindness according to degree of vision and social factors.

Mr. Goldberg indicated that additional comments about some of these and other studies in which the Biometrics Branch is participating would be discussed by other Branch personnel during the Conference.

b. RESEARCH ACTIVITIES

1. Study of Association of Perinatal Factors with Strabismus in Negro Children

C. Morton Hawkins, Statistician,
Biometrics Branch, NINDB.

Mr. Hawkins informed the conferees that the strabismus study, being conducted jointly by the Biometrics Branch and the University of Maryland's School of Medicine, was nearing completion. The study which has been described in detail in the Proceedings of the Second Annual Conference of the Model Reporting Area, is a retrospective one of Negro children with strabismus, born in Maryland (principally in Baltimore) who were thirteen years of age or under, and of controls matched on variables such as place of birth, date of birth, sex, race, and maternal age. Mr. Hawkins indicated that all original matched controls who died in the neonatal period were replaced by appropriately matched neonatal survivors.

The two main objectives of the study were to determine whether the mothers of children with strabismus were different from the mothers of control children in reported prenatal and obstetrical complications, and to determine whether the distribution of birth weights of children with strabismus was different from that of the control group. Also, the cases and matched controls would be compared on variables such as postobstetrical history; fetal presentations and positions; type of delivery; length of labor; toxemic, hemorragic, mechanical, and medical complications of delivery; reported abnormalities of the infant; and reported length of gestation.

Mr. Hawkins noted that the study included 406 cases and their matched controls. Although delayed because of limited access to certain hospital records, all data had been collected, coded, and recorded on IBM cards.

He concluded by indicating that analysis and interpretation of the data was underway and would be completed in the next few months. The results of the study will be presented at the next annual meeting of the American Public Health Association.

2. Study of Survivorship and Causes of Death Among the Blind in Massachusetts

Eugene Rogot, Statistician, Biometrics Branch, NINDB.

Mr. Rogot noted that some of the details of the Massachusetts Survivorship Study were described at previous MRA conferences and appear in the Proceedings of those annual conferences. A detailed report on this study has been submitted for publication in the Journal of Chronic Diseases, and will appear there in the near future. Mr. Rogot summarized the major findings.

A follow-up study of 11,732 persons first registered as legally blind in Massachusetts during the 20-year period, 1940-1959, was conducted in order to determine survival rates, sight-restored rates, and probabilities of dying from major causes of death for the blind. Blind persons experienced poorer survivorship than expected at all ages up to 75, with little if any difference apparent at ages 75 and over. Marked differences were noted for ages 25-64. Survival rates for persons with diabetes as the cause of blindness were extremely low in comparison with the general population. The causes of death among the blind which especially showed large excesses in mortality over that expected, were diabetes and heart disease. Sight-restored rates were in general rather low. Throughout, findings were similar for males and females. Mr. Rogot noted that, in the paper to be published, data were compared with material from two previous studies. Also included in the paper are a discussion of limitations of the present study and suggestions for further research. In commenting on the further research suggested, Mr. Rogot posed a number of questions arising from the survivorship study, each of which may be investigated in its own right. These questions were as follows:

(1) Do survivorship patterns observed for blind white persons in Massachusetts generally hold for other geographic areas and for nonwhite persons?

(2) Why is there a difference in survivorship by age (i.e., with regard to the observation that those blind persons under 75 have poorer survival rates than expected but those 75 and over do not)?

(3) Why is there a distinct difference in survivorship prospects by age for persons with glaucoma (i.e., with regard to the observation that those under 65 have lower survival rates than expected but those 65 and over do not)?

(4) Why is survivorship so poor among the diabetic blind?

(5) How does survivorship among the diabetic blind compare with diabetics who are not blind?

(6) Why do persons with unknown cause of blindness have poor survivorship?

(7) Why do blind females 65 years of age and over, and blind males 75 and over, have lower cancer mortality than expected?

(8) Why do blind females 75 years of age and over have lower heart disease mortality than expected?

(9) With the possible exception of the 5-14 age group, why are sight-restored rates so low?

(10) How does survivorship among the totally blind compare with that of the general population?

DISCUSSION

Mr. Friedensohn inquired as to whether the lower survivorship rates for the diabetic blind were based on a comparison with the total general population or the diabetics in the general population. Mr. Rogot stated that the comparison was with the total general population and the lower survivorship was to be expected since these blind persons had diabetes. He noted that a key comparison to be made was between the diabetic blind and the general diabetic population.

3. Tonometric Surveys

Geoffrey Dell'Osso, Statistician, Biometrics Branch, NINDB.

Mr. Dell'Osso noted that the Biometrics Branch has been assisting in the statistical analysis of two tonometric surveys. Under the direction of Dr. Schwartz, Head, Section on Ophthalmic Field and Developmental Research, Epidemiology Branch, NINDB, field teams have recently completed examinations of 500 Italian-Americans in Nesquehoning, Pennsylvania, and of over 440 Indians on a reservation in Arizona. Each group comprises about 85 percent of the total available study population. Tonometry was performed not only with the widely used Schiotz indentation type instrument, but also with the Goldmann applanation tonometer used in both sitting and supine positions. Repeated readings were taken with both instruments so one could more clearly judge their accuracy and dependability. The aims of these surveys are, first, to establish with a high degree of accuracy the distribution of ocular tensions in the study populations to serve as control information for collaborative studies and surveys protracted over time, and to provide information regarding ethnic and environmental factors as they influence the epidemiology of chronic simple glaucoma. The second major aim was to compare results of the three methods of tonometry and to examine and analyze the differences among the methods, with the goal of defining the postural influence on ocular tension and assessing the compatibility of instruments and methods of measurement as they affect individual tension levels and survey screening procedures.

4. Study of Attitudes, Awareness, and Performance of Blindness Reporting Sources

Richard E. Onken, Research Assistant, American Foundation for the Blind.

Mr. Onken summarized briefly the status of the study being conducted jointly by the American Foundation for the Blind and the Biometrics Branch on attitudes, awareness, and performance of blindness reporting sources. Details regarding the nature of the study are contained in the Proceedings of the Third Annual Conference of the Model Reporting Area. Mr. Onken stated that approval was being obtained for the use of the questionnaires designed for the study. After the questionnaires have been cleared for use, the interviews will be initiated. Although it was originally planned to limit the study to eight States with blindness registers, these plans were changed to include all 28 States with laws requiring them to maintain such registers. This will include all States represented at the MRA Conference except the District of Columbia and Georgia whose registers are in the process of being developed. Arrangements are being made for interviews with representatives of the register agencies, the State supervising or consulting ophthalmologists, and a sample of ophthalmologists and optometrists in each of the 28 States.

5. Blindness Register Demonstration Project in Egypt

Dr. Hyman Goldstein, Chief, Biometrics Branch, NINDB.

Dr. Goldstein reported that an agreement to collect data on blindness in Egypt had been negotiated with the University of Alexandria, Alexandria, Egypt, by the National Institute of Neurological Diseases and Blindness and that the project would complement and extend the efforts of the Institute's Model Reporting Area for Blindness Statistics which is attempting to collect comprehensive data on the blind population in this country. The project would collect data on incidence as well as prevalence of blindness.

Although the development of reliable blindness statistics in this country is of great importance and a prime objective of the MRA, it is obvious that great value would reside in a development of similar statistics in other countries, particularly in those areas where blindness is a major problem. In order to be able to compare these figures with those collected by the MRA, the data must be collected in the same manner and meet the same standards of accuracy and completeness. The definition of blindness used would be the same as that used by the MRA. Data from the Egyptian project when compared with those of the blind population in MRA States would serve as a guide for research needs and offer clues to specific blinding disorders in this country. The high incidence of blindness in Egypt make it a particularly desirable place to evaluate the role of environment in causing blindness. In addition, the opportunity to secure data comparable to those secured by the MRA might provide new clues to etiology. The agreement between the University of Alexandria and the NINDB provides for a pilot blindness register to collect statistics on blindness and severe vision impairment in two urban areas in Alexandria, Egypt, and a number of rural communities outside of Alexandria. Upon completion of this pilot study, the University plans to extend the register to other areas of Egypt with the help of the Egyptian Government.

This study would help to determine what modifications might be made in MRA data collection procedures when applied in other countries, particularly those that are underdeveloped, and still produce statistics in those countries comparable with those collected in this country. It is hoped that the proposed pilot study will serve as a laboratory to procure needed information relating to variables associated with incidence and prevalence that can be evaluated statistically with respect to prevention activities. The study, scheduled to last three years, is financed by Public Law 480 funds. It is obvious that blindness prevalence and incidence rates by specific cause, age, sex, and other demographic variables would be invaluable to programs of prevention by pinpointing those high risk population groups that should be screened for early signs of such impairment. It is planned to have a house-to-house visual screening survey to be followed by examination in an ophthalmological clinic of those found to have severe vision impairment. Such surveys would also determine which demographic groups are being underreported to the register. These groups might later be targets for educational campaigns to encourage people to seek early medical help and hopefully prevent much of the blindness. For the house-to-house survey it is imperative that the screening procedure be based on more objective evidence than a respondent's statement that either he or others in the household are blinded; and, in this connection, a portable vision tester would provide objective visual acuity testing in the home. The use of such a vision tester ensures standard lighting and distance as well as privacy during such examination. The vision tester to be used in this pilot study has already been modified so that it can be used equally well in homes with or without electricity and in homes using either 110 volts or 220 volts. It is planned that the survey would also include refraction (without drops) to secure best correction, and measurement of peripheral field vision by means of portable perimetry. All of the factors that enter into a definition of blindness, such as that used by MRA, namely visual acuity, best correction, and visual field, would be objectively measured in the home by trained examiners.

When combined with scientific sampling of households, one could obtain reliable estimates of incidence and prevalence of blindness with a known degree of sampling error. The procedure can be used both in community surveys in this country as well as abroad in developing countries. It could make available sophisticated statistical data on blindness in areas such as underdeveloped countries with high rates of blindness, where, hitherto, statistics have been poor.

The ophthalmologist would examine all cases screened and suspected of blindness not only to confirm the visual acuity, refractive, and perimetric data obtained by survey, but also to reach a diagnosis and possibly the underlying cause of the condition. All such examinations would be recorded on standard eye examination forms, namely the form recommended by the National Society for the Prevention of Blindness.

Tests of the reliability of vision examiners and of the ophthalmologists would be made before the study started and periodically throughout its duration to ensure uniformity in visual testing by examiners and in diagnoses by ophthalmologists. Furthermore, periodically throughout the study, a sample of cases would be reexamined by examiners and ophthalmologists as a continuing spot check on accuracy. The classification of all diagnoses by site/type and etiology will be accomplished by one physician-statistician and checked by another, both trained in the use of the Standard Classification of Causes of Severe Vision Impairment and Blindness. Their classification would be reviewed by the Biometrics Branch to maintain adherence to principles in use of the Standard Classification.

Since it is obvious that it is not feasible to survey the whole Egyptian population or even a representative sample, the pilot study would be limited to two areas in the city of Alexandria with a population of approximately 125,000 people (approximately 25,000 households). These two areas represent a variety of socio-economic statuses ranging from the poorest to the wealthiest. In addition, 23 nearby villages would be included as the rural part of the study and would also account for some 125,000 people (approximately 25,000 households). Only permanent, non-institutionalized residents were to be included.

The project, which started March 1, 1965, has three phases. Phase I consists of the visual screening of a random sample of 2,000 households consisting of about 10,000 persons. This sample would include persons from urban and rural areas, roughly 1,000 households in each. A listing of all households in the urban and rural areas would provide an up-to-date, complete frame of households from which to sample. Such a household survey in Phase I would yield baseline prevalence rates on binocular blindness by age, sex, visual acuity, and other demographic variables for the urban and rural populations separately, as well as crude and age-sex standardized rates to be compared with the corresponding rates of Phases II and III.

The purpose of Phase II would be to build up a blindness register and would be started by a publicity campaign in a drive to get everyone in the study areas, that is, approximately 250,000 people, to come voluntarily to either the health centers or the University hospital for visual screening tests identical with those given in Phase I. If a person is bedridden or infirm, the test would be given in his home. The same test procedures as in Phase I would be used. Any person suspected of being blind in this voluntary screening would also be examined ophthalmologically, either in the health centers, the University hospital, or at home. In addition, ophthalmologists in all agencies, hospitals, and clinics serving the blind in these areas would be canvassed for any information on the known blind and would be encouraged to report blind cases to the register on a continuing basis. The results of the screening in Phase I would be compared with the screening of the entire study population in Phase II. Thus, it would be possible to get some idea of which demographic groups by age, sex, and geography are not coming in as expected for visual screening tests. This will permit better focusing of educational efforts to bring about completeness of voluntary screening.

Phase III, the last phase, would be a repeat of Phase I by rescreening the same sample of 10,000 persons of Phase I, that is, those who were still alive and still resident in the study areas. After a level of stability had been reached in the prevalence of binocular blindness as shown in Phase II, such reexamination would determine new cases of blindness that would have developed in the interval and would determine which blind persons from Phase I would have had their vision restored and which would have died or moved out of the study areas. Comparison of Phases I and III would permit the calculation of incidence of blindness by cause, visual acuity, age, sex, and other demographic variables, as well as crude and age-sex standardized rates for both rural and urban populations.

Throughout the period of the study no prevention of blindness activities would be started in the study areas in order to arrive at findings uncomplicated by new variables. Emphasis would be placed on standardization of procedure in the uniform collection of data and thus assure, as far as possible, the comparability of data between the MRA and the Egyptian pilot study. The pilot register would furnish information on trends and causes of blindness for comparison with MRA data. Any modification of MRA procedures applied in Egypt that might be required in order to operate within the pilot study environment there, and still permit the production of statistics comparable to those of the MRA, would be fully documented. It is expected that this study would provide information to indicate the extent to which data collection procedures in a highly developed country may and should be modified so that, for purposes of statistical evaluation, they are usable in a less sophisticated environment.

VI. THE MODEL REPORTING AREA QUALITY CONTROL PROGRAM ON CODING OF CAUSES OF BLINDNESS

Helen B. Moorhead, Medical Record Librarian, Biometrics Branch, NINDB.

Mrs. Moorhead stated that at the Workshop on the coding of causes of blindness which had been held at the National Institutes of Health in February 1965, Dr. Ralph G. Hurlin, Chairman of the Sub-committee on Classification of Causes of Blindness of the National Society for the Prevention of Blindness had said, "It is wise to remind ourselves frequently that statistics are manufactured products and that the procedures used in producing them have controlling influence on the quality of the product. Poor procedures yield poor statistics and better methods are likely to produce better statistics. But good methods when different can produce data that are different enough in composition to make their comparison or combination invalid."

At the Third Annual Conference of the Model Reporting Area for Blindness Statistics, Mrs. Moorhead recalled, the need was recognized for a Quality Control Program to assure uniformity and comparability of the data on causes of blindness and severe vision impairment in the Model Reporting Area. It had become apparent that differences among the individual coders in interpretation of reports and applications of coding principles was hindering the objective of producing statistics in each State that could be compared with those from every other State. These differences were underscored when punch cards became available for 1963 data which made it possible, for the first time, to make detailed comparisons of specific categories, State by State. These detailed tabulations were again made in 1964, and the data showed in cataracts, for instance, that some States did not classify etiology of any as "unknown to science," while others placed more than 70 percent in this category. The situation was reversed for "senile degeneration." The States with a large percentage classified to "senile degeneration" were usually those which had very few under "unknown to science." The same thing held true for glaucoma. The categories for "etiology not reported or determined" showed wide fluctuations in the 1964 report. A number of States showed seven percent or less of cataracts with the cause not reported or determined, while others had over 60 percent. For glaucoma, some had no cases with the etiology not reported, and others had more than 50 percent. Mrs. Moorhead said that these large differences almost certainly reflect coding practices. The number of cases of cataract and glaucoma is large, and such variations are easily seen in a detailed machine tabulation; however, more subtle differences can be found only by examination of individual eye reports.

It was felt that review of coded reports at a central point would identify the specific areas where differences were occurring and furnish the information necessary to develop measures to produce uniformity. In February of this year Dr. Goldstein wrote the member States that the Biometrics Branch was prepared to launch a Quality Control Program and furnish this central review. The response in submitting coded eye reports for review was prompt, and in fact overwhelming, Mrs. Moorhead said. In no other way can the Biometrics Branch be aware of problems encountered, their differences and their similarities, and work toward developing procedures which will ensure that a given report will be coded the same in each of the member States. This is not a simple matter. Loss of vision is frequently due to a complex of causes, and this complexity poses many and varied questions in classification. At the recent Workshop some of these were discussed and resolved. It was also found that some were not easily resolved and would require further study.

The revisions of the Classification and Index which were introduced for use beginning this year are designed to eliminate some of the variations that were obvious. They also incorporate changes which hopefully will eliminate some of the major complaints which were voiced by consulting ophthalmologists and by users of the previous revision. One such change is the restoration of the category for multiple congenital malformations. Others are the provisions for discriminating between open and closed angle types of glaucoma and between an unoperated and operated cataract.

Many people had asked, "How do we classify a diagnosis of cataract and glaucoma or glaucoma and retinopathy when we have no information to tell us which is impairing vision or which first caused severe visual impairment?" Two possible approaches were suggested. One, to rule arbitrarily which condition was to be coded. Two, to provide codes that would show the coexistence of the conditions. It was felt that the latter approach would furnish more valuable information, and so categories for multiple affections had been introduced into the revised Classification. These categories are not intended to supplant the basic principle of classifying the one underlying condition which first led to severe visual impairment, whenever this is possible. They were not designed for use in all cases in which cataracts and glaucoma or cataracts and retinal disease are reported together, and are meant only for those instances in which it is impossible to determine which condition first caused blindness.

The fear has been expressed that these categories will become a dumping ground, the easy way out, and will cause the loss of valuable information instead of serving their intended purpose of being a protection against this. There must be continuing surveillance to guard against such loss. This is a legitimate fear, and one of the objectives of the Quality Control Program will be to develop procedures to aid in the uniform selection of a single underlying cause of blindness and avoid, whenever possible, the use of the multiple categories. This would not be possible without the opportunity to see and compare a large number of actual eye reports.

A continuing obstacle to the uniform selection of the underlying cause is the various forms in use for reports of eye examinations in different States. This variety makes it difficult to standardize classification rules. Some forms ask only for diagnosis; others specify primary and secondary diagnoses. Neither of these solicits diagnostic information in a manner which will delineate the affection which first led to blindness. The Physician's Report of Eye Examination, developed by the Nation Society for the Prevention of Blindness, has a section for diagnosis which was specifically designed to identify the responsible underlying affection and its etiology. A number of States use this report or have included parts of it in their State forms. Mrs. Moorhead said that it was hoped that those who could not adopt this form in its entirety would incorporate essential elements of it, in particular the diagnostic section, in future revisions of their eye examination report.

Mrs. Moorhead stated that considerable study had been given to the more than one thousand reports which had been sent in already on the Quality Control Program. Some reports had already been returned to the States with comments on recommended coding changes. Some were being retained for referral to the consulting ophthalmologist, and it was planned to send the remainder back within the next few weeks.

While classification of causes of blindness is not new, and numerous such studies have been done, the Model Reporting Area is unique in that many people in widely scattered areas are classifying the data instead of its being done at a central point. For the most part, the classifiers have had little or no communication with one another and have had no means of knowing to what extent their methods differed and to what extent they were similar. Mrs. Moorhead emphasized that this unique situation also presents a unique opportunity, that of bringing together these varied practices and standardizing them so that it will be possible for many people working independently in their own areas of influence to know that their work has a wider interest than their immediate locale. She said that it is the aim of the Model Reporting Area Quality Control Program to grasp this opportunity and work toward the attainment of the goal of standardization.

VII. PROBLEMS RELATING TO VISUAL FIELD CRITERIA IN THE DEFINITION OF BLINDNESS

a. Evaluation of Visual Field Criteria in the Definition of Blindness by State Consulting Ophthalmologists

Irving D. Goldberg, Assistant Chief, Biometrics Branch, NINDB. (See Appendix C for this paper.) A summary of the paper appears below.

SUMMARY

Mr. Goldberg noted that the Third Conference of the Model Reporting Area included a discussion of the definition of blindness. Specifically, the discussion dealt with that portion of the definition relating to field of vision, namely, "visual acuity of more than 20/200 if the widest diameter of the field of vision subtends an angle no greater than 20 degrees." The question at issue was concerned principally with the interpretation of what constitutes a 20 degree limitation. For purposes of orientation Mr. Goldberg commented on the origin of the current definition.

The discussion at the Third Annual Conference led to a proposal that the Biometrics Branch utilize the resources of the Model Reporting Area in an effort to clarify the existing definition so as to arrive at a uniformly acceptable definition. In keeping with this recommendation, the Biometrics Branch obtained the cooperation of the 17 member and nonmember States participating in the MRA program. The directors of the blindness programs in each of the States obtained from their consulting ophthalmologists comments regarding interpretation of the definition of field of vision. The responses which were received from 23 ophthalmologists in the 17 States, were submitted to the Biometrics Branch for review.

The attempt to arrive at a resolution of the basic problem was based on four questions which were directed to the participating ophthalmologists as follows:

1. How does he interpret the angle subtended in the widest diameter of remaining field of vision (e.g., in terms of diameter, radius, point of fixation, etc.)?
2. How does he apply to the definition of blindness those conditions where vision is not present in all four quadrants (such as in hemianopsia)?
3. In the examination for field of vision, what size and color of target used are acceptable, at what distance, and by what method (e.g., perimeter, tangent screen)?
4. What other specific factors are considered when determining whether a person is blind by reason of field restriction?

Mr. Goldberg presented and discussed a summary of the responses to these questions (see Appendix C). It was evident that variation existed in interpretation of the blindness definition relating to field of vision and there was no apparent simple solution to the problem. It was suggested that the MRA States continue to use their present guidelines with the advice of their consulting ophthalmologists. In the meantime, insofar as possible, the MRA will pursue this matter further towards a suitable resolution of the problem.

b. Considerations Relating to Visual Field Criteria in a Definition of Blindness

Dr. Austin Lowrey, Jr., Project Ophthalmologist, Blinded Veterans Research Project, American Foundation for the Blind—Veterans Administration. (See Appendix D for this paper and discussion which followed.) A summary of the paper appears below.

SUMMARY

It was pointed out that it is time now to create a new definition of blindness because the one in use only embodies two elements of visual function (distant visual acuity and central fields of vision) and no standardization is required in measuring either of them. This fact has resulted in the present definition being ambiguous and difficult to interpret.

The question was raised as to what levels of vision and size of fields should be included in a definition of blindness, and whether the new definition should be called "A Definition of Blindness," or "A Definition of Blindness and Severe Vision Impairment."

It was suggested that in the new definition of blindness, providing the present levels of vision and fields are retained, other visual elements be included in the definition, namely, extra-ocular muscle function, fusion ability, depth perception, adaptation, color vision, accommodation, convergence, etc.

Several methods of measuring fields were mentioned, and it was pointed out that the method used must be correlated with the pathology and other conditions present.

It was emphasized that the size and color of test and fixation objects had to be correlated to the level of visual acuity present and distance used.

In interpreting the visual fields it was emphasized that the size and shape of the areas of the field and their relationship to the point of fixation, as well as the size, shape, and position of scotomas in the field with their relationship to the point of fixation, were most important considerations and give a better basis for judging visual function than just the greatest diameter of a field alone.

In closing, Dr. Lowrey stressed how important it was to have a reliable "yardstick" in a definition of blindness developed now, so that the blindness statistics gathered in the Model Reporting Area would be more accurate and meaningful.

VIII. SYMPOSIUM—BLINDNESS STATISTICS IN PROGRAM PLANNING

a. FEDERAL GOVERNMENT

1. Library of Congress

Robert S. Bray, Chief, Division for the Blind, Library of Congress. (See Appendix E for Mr. Bray's paper and discussion which followed.) A summary of the paper appears below.

SUMMARY

Mr. Bray noted that one of his main goals as an administrator in the Library of Congress' Talking Book program is to reach at least 50 percent of the blind people eligible for this service. He stressed the importance of statistics in determining the extent to which the goal had been met and in determining those persons not yet reached by the service. He illustrated how this goal can be measured, utilizing data on the number of readers and the available blind population estimates by State. From these statistics, only in five or six States are approximately 50 percent or more of the known blind population receiving the reading service. Vermont, with 65 percent of its estimated known blind population receiving the reading service, leads the nation; the other States with about 50 percent or more of their known blind persons availing themselves of the reading service are Oregon, Utah, Nebraska, Montana, and Delaware. Mr. Bray concluded by stating that he saw the statistics produced by the Model Reporting Area as a valuable tool in determining the extent to which the Library of Congress' Talking Book service reaches its potential clientele.

2. Vocational Rehabilitation Administration

Douglas C. Mac Farland, Ph.D., Chief, Division of Services for the Blind, Vocational Rehabilitation Services, Department of Health, Education, and Welfare. (See Appendix F for Dr. Mac Farland's paper.) A summary of the paper appears below.

SUMMARY

Dr. Mac Farland noted that for the past quarter century data processing equipment and sophisticated electronic computers have brought the science of mathematics and statistics into practically every field of study. Yet, in spite of the long history of work for the blind, exact information is not available regarding the number of blind persons in the country nor the reasons for their blindness. Dr. Mac Farland felt that it was inexcusable in this day of advanced physical and social sciences that exact data cannot be provided on such a relatively small number of the total population.

He stressed that the Vocational Rehabilitation Administration (VRA) had currently in Congress legislation which, if enacted into law, would have far reaching effects on the disabled and, specifically, the multidisability groups in this country. He felt that this would provide a great impetus to the State-Federal partnership in constructing and staffing workshops for those who are unable to engage in outside competitive employment. The VRA would be in a good position to build, equip, and operate work opportunity centers for the development of the skills of the multiply handicapped who will eventually become productive workers in sheltered workshops, or who may even progress to outside competitive employment. In addition, the law would permit the VRA to engage in constructing and staffing comprehensive rehabilitation centers for the blind. Dr. Mac Farland indicated that at present there are approximately 22 such centers with a capacity for serving 1,000 individuals per year. Further, plans are being developed to double the number of rehabilitation centers within the next ten years with a more comprehensive program which will be able to serve more clientele, at least 3,000 persons by 1975.

Although it is not impossible to plan intelligently on the basis of statistics now available, Dr. Mac Farland felt that it would be much more helpful if it were known exactly how many blind persons there are to be served and the extent of the disability, the current age, age at onset of blindness, cause of blindness, and other handicapping conditions present, along with an analysis of which blinding conditions are increasing in certain age groups. For example, Dr. Mac Farland pointed out that the VRA had noticed a vast increase in the number of persons with diabetes who are now requesting services at the rehabilitation centers. He believed that exact calculations would be most helpful in future planning of the rehabilitation centers, and that the whole picture of physical restoration in the rehabilitation services would be vastly improved if all States had registers similar to those in the MRA States.

As a further illustration of what registers could mean in each State, Dr. Mac Farland noted their value in conjunction with the VRA plans for expanding its approximately 25 optical aid centers to a total of approximately 65 during the next ten years.

According to Dr. Mac Farland, two areas in which the expansion of training facilities is vital are home teaching and mobility instructions. He estimated that there are many thousands of blind persons who need travel training. He stressed that personnel necessary to give these two types of instruction cannot be filled by the limited number of graduate schools offering this type of professional training.

Dr. Mac Farland indicated that he could not emphasize too strongly how vital it will be for those persons working in the blindness field to have exact statistics on which to base programs for serving blind persons. He noted that, at present, all of the calculations and plans made by the VRA are based on educated guesses.

In conclusion, he stated that it was his fervent hope that within the next three years there would be full representation from all States and territories in the Model Reporting Area program and that information would be so recorded that if one wished to know, for example, the number of cataract cases in the country, those suffering from diabetic retinopathy, the age distribution, or any other vital statistic which is necessary in order to serve blind clientele, it could be provided within a matter of hours.

3. Welfare Administration

Robert H. Mugge, Chief, Demographic Research Group, Division of Program Statistics and Analysis, Bureau of Family Services, Welfare Administration, Department of Health, Education, and Welfare. (See Appendix G for Dr. Mugge's paper and discussion which followed.) A summary of the paper appears below.

SUMMARY

Dr. Mugge stated that many agencies administering programs of Aid to the Blind fail to seek or to use the information which is needed in order to make intelligent decisions in program administration. However, the Bureau of Family Services, through its research division (the "Division of Program Statistics and Analysis"), is attempting both to obtain the kinds of program and general social data most needed for program administration and to help agencies to make the best use of these data. Basic program data are obtained through periodic statistical reports which give the Bureau the "big picture" as to what is being done in and through Aid to the Blind, where the program has been and where it is headed. These reports provide data, on a national, State, and county basis, as to the number of recipients and the amount of payments. On a State by State basis, information is periodically obtained as to applications and their disposition, reasons for opening and closing cases, kinds and amounts of medical care provided, agency staffing, expenditures for administration, sources of funds spent, services provided, budgeting standards, and the like.

In addition to the periodic statistical reports, the Bureau conducts occasional surveys and other studies dealing with the several public assistance programs. In 1962 a nationwide survey was conducted into the States' Aid to the Blind programs. A great deal of information was obtained through this survey on demographic characteristics of the recipients, their living arrangements, education, work history, special services received, duration of assistance, physical or mental conditions, financial circumstances, and degree, duration, and causes of blindness. The values of such information to one wishing better understanding of the Aid to the Blind programs and the people being served by them seem obvious. General findings of the study were presented in an article titled "Recipients of Aid to the Blind," published in the April 1965 *Welfare in Review;* reprints of this article are available on request. State comparisons of statistical findings are also available in the report of the Bureau of Family Services titled "Characteristics of Recipients of Aid to the Blind; Findings of the 1962 Survey: State Tables," June 1964. Additional analytical reports of survey findings are planned.

b. STATE GOVERNMENT

1. Oregon Commission for the Blind

Clifford A. Stocker, Administrator, Oregon Commission for the Blind. (See Appendix H for Mr. Stocker's paper and discussion which followed.) A summary of the paper appears below.

SUMMARY

Mr. Stocker noted the increasing importance of reliable blindness statistics in program planning and development to improve services for the nation's blind population.

These statistics can only be derived from a carefully compiled and meticulously maintained set of reliable records. Mr. Stocker stated that it is the responsibility of each State to develop the best possible set of blindness statistics, and he suggested that the MRA offers a means by which this can be accomplished.

The register in Oregon has proved valuable in a variety of ways. Statistics derived from the register were helpful in answering inquiries about the extent and causes of blindness and what can be done about it. These inquiries have come from such groups and individuals as voluntary service groups, medical schools and other medically oriented organizations, social work agencies, schools and colleges, State legislators, newspapers, etc. The register has also been used advantageously by other State and local agencies in Oregon. Mr. Stocker illustrated by actual example how the register was used effectively.

The State Motor Vehicle Department, in response to proposed legislation, requested the Commission to assist it in determining whether any licensed drivers were blind. The Commission was able to provide the Motor Vehicle Department with names and addresses of its registrants, and set up a procedure to provide that Department with similar information monthly on new additions to, and removals from, the register. Where deemed necessary, the Department secures visual examinations of licensees who are on the blind register. The State Board of Health is also involved in this inter-agency activity because of its statutory responsibility in reviewing medical examination reports on applicants for special or restricted driver's license. The results of these examinations and the Board of Health rulings are made available to the Commission for proper action regarding its register. It is hoped that a by-product of this inter-agency activity will result in legislation (e.g., budget) to enable the Commission to start programs for servicing the visually impaired who are not yet legally blind.

Mr. Stocker also indicated how the blind register can be used to determine the number of blind persons on various public assistance programs, such as Old Age Assistance. This rapport with welfare agencies will help, through referrals, to keep the blind register current and accurate.

In closing, Mr. Stocker noted how statistics derived from the register are useful for planning the Commission's biennial programs for the blind. This includes budget and personnel needs, as well as appropriate emphasis on specific program activities. Particular note was made of the potential which reliable statistics provide for long range planning. Mr. Stocker concluded that the value of these statistics justifies the efforts expended in compiling and maintaining the essential data.

2. Vermont Department of Social Welfare

   Virginia Cole, Director, Division of Services for the Blind, Vermont Department of Social Welfare. (See Appendix I for Miss Cole's paper.) A summary of the paper is given below.

SUMMARY

In her opening comments Miss Cole noted how unlikely it seemed that efforts would be made to gather statistical data about people without correlating this with the activities aimed at serving these people. It was evident to her from discussion at the Conference alone that registers and program activity were closely allied. In noting that no one agency could foresee all uses to which data might be put, Miss Cole directed her presentation in the form of a questioning or searching for further thought and discussion.

With regard to program activity, Miss Cole stressed the importance of constant program evaluation in terms of accomplishments, current activity, and plans for the future. Data such as that produced through the MRA can be extremely helpful, particularly as an aid in planning for the future. One must acknowledge the distinction between the gathering of data and the using of it in developing programs to serve people with problems.

In her presentation Miss Cole raised a

series of specific questions in relation to a variety of blindness statistics to illustrate how such data can be used effectively in program planning. For example, she illustrated how blindness statistics by age groups can be geared to meeting the specific needs of blind persons in the different age levels, such as in planning for their education, rehabilitation, or adjustment to loss of sight. She pointed out how data by sex may affect plans relating to facilities for rehabilitating homemakers. She also related statistics on etiology to various intra- and inter-agency programs concerned with a variety of disorders or handicaps (e.g., diabetes, hard of hearing, brain damage, etc.); statistics on degree of vision with optical aid programs; statistics on type of residence with workshop, employment, mobility, and other program considerations; etc.

Miss Cole described by actual example how blindness statistics can be of value to State legislators; and how effective utilization of these statistics in news releases, pamphlets, and annual reports can result in legislative and public support of the agency's activities. She also noted that blindness statistics derived from the MRA have enabled her to provide a variety of data requested by various individuals and agencies, which would not otherwise have been available.

IX. MODEL REPORTING AREA TABULATIONS—PROGRESS AND PLANS

a. REPORT OF PRELIMINARY TABULATIONS FOR 1964

Ronald L. Jacobson, Statistician, Biometrics Branch, NINDB.

(Note.—Due to the preliminary nature of the tabulations presented and discussed at the Conference, and to avoid subsequent confusion, the summary and discussion of the presentation by Mr. Jacobson which follow are limited to the general aspects and implications of the 1964 preliminary tabulations. However, a final detailed report of the 1964 tabulations of the Model Reporting Area for Blindness Statistics will be published as a separate document.)

Mr. Jacobson reported that the preliminary tabulations represented data which were submitted by all 12 of the Model Reporting Area States. He further indicated that since New Mexico was in the process of completing its register during 1964, and therefore unable to provide data on additions to and removals from the register for the entire year, data for New Mexico would be confined only to those tabulations relating to total on the register at the end of the year.

The 26 tables presented were summarized by Mr. Jacobson as follows:

Table 1: Summary data.

Tables 2-19: Register additions in 1964. In this group of tables there were nine tables on cause of blindness.

Tables 20-25: End-of-year total on the register.

Table 26: Register removals during the year.

The conferees were reminded that the tables concerned with cause of blindness pertaining only to those first additions to the register during 1964 who had been examined by ophthalmologists or eye-ear-nose-and-throat specialists.

The titles of the tables presented and discussed were as follows:

1. Summary table of first additions, readditions, removals, and end-of-year total on register: each MRA State and MRA total, 1964.
2. All additions to register by age and sex: MRA total, 1964. (Number and rate.)
3. All additions to register by sex and race: each MRA State and MRA total, 1964. (Number and rate.)
4. All additions to register by age: each MRA State and MRA total, 1964. (Number and rate.)
5. All additions to register by degree of vision: each MRA State and MRA total, 1964. (Number and percent.)
6. All additions to register by sex, race, and degree of vision: MRA total, 1964. (Number and percent.)
7. All additions to register by age and degree of vision: MRA total, 1964. (Number and percent.)
8. First additions to register by age at onset: each MRA State and MRA total, 1964. (Number and percent.)

9. First additions to register by discipline of examiner: each MRA State and MRA total, 1964. (Number and percent.)
10. First additions to register by degree of vision and discipline of examiner: MRA total, 1964. (Number and percent.)
11. First additions to register by major affection groups: each MRA State and MRA total, 1964. (Number and percent.)
12. First additions to register by sex, race, and major affection groups: MRA total, 1964. (Number and percent.)
13. First additions to register by age and major affection groups: MRA total, 1964. (Number and percent.)
14. First additions to register by degree of vision and major affection groups: MRA total, 1964. (Number and percent.)
15. First additions to register by major etiology groups: each MRA State and MRA total, 1964. (Number and percent.)
16. First additions to register by sex, race, and major etiology groups: MRA total, 1964. (Number and percent.)
17. First additions to register by age and major etiology groups: MRA total, 1964. (Number and percent.)
18. First additions to register by degree of vision and major etiology group: MRA total, 1964. (Number and percent.)
19. First additions to register by major affection groups and major etiology groups: MRA total, 1964. (Number and percent.)
20. Total on register by age and sex: MRA total, as of December 31, 1964. (Number and rate.)
21. Total on register by sex and race: each MRA State and MRA total, as of December 31, 1964. (Number and rate.)
22. Total on register by age: each MRA State and MRA total, as of December 31, 1964. (Number and rate.)
23. Total on register by degree of vision: each MRA State and MRA total, as of December 31, 1964. (Number and percent.)
24. Total on register by sex, race, and degree of vision: MRA total, as of December 31, 1964. (Number and percent.)
25. Total on register by age and degree of vision: MRA total, as of December 31, 1964. (Number and percent.)
26. Removals from register by reason for removal: each MRA State and MRA total, 1964. (Number and percent.)

DISCUSSION

Mr. Friedensohn inquired as to whether any comparisons were made between MRA data and Dr. Hurlin's estimates for 1960. Mr. Goldberg noted that comparisons can only be made for end-of-year totals since Dr. Hurlin's estimates were limited to prevalence. He said that although there may be one or two exceptions, Dr. Hurlin's estimates for the MRA States were generally larger than the actual register prevalence for the respective States. According to Mr. Goldberg the reasons for this difference related to the basis on which the estimates were made by Dr. Hurlin, the status of the North Carolina register (on which Dr. Hurlin's estimates were largely based) at the time he made the estimates, and the question of completeness of reporting to the registers. It is possible that lack of adequate updating of the North Carolina register at that time may have accounted largely for Dr. Hurlin's higher estimates. However, Mr. Goldberg emphasized the importance of studies on completeness of reporting to determine if there is under-reporting to the MRA registers, and if so, the extent to which the MRA registers may understate the actual prevalence.

Mr. Kohn suggested that consideration should probably be given to the vision groupings which might be used to distinguish between blind persons with considerable loss of useful vision and those with a greater amount of remaining useful vision. Thus, the MRA may wish to use acuity of 5/200 or less as a meaningful criterion for describing those with considerable loss of useful vision. Such statistics would be helpful in directing programs relating to useful vision.

This led to a general discussion of functional vision, the problems of defining functional or useful vision, and the value of statistics based on different criteria for identifying those with little useful vision. Thus, Mr. Kohn indicated the value of visual acuity criteria (e.g., 5/200) in identifying the very visually impaired for purposes of better orientation of a total program for the legally blind. It was evident from the discussion that this was not in conflict with the separate need for a better definition of functional vision. For example, Dr. Graham mentioned that while the 5/200 criterion is commonly used, a definition of severe functional loss based on medical criteria and other tests which may be available would be very helpful. He further noted that for research purposes it is more meaningful to know if there is any useful vision at all, and he indicated that the term "useful" vision has a different meaning depending on whether one is concerned with mobility, reading, etc.

Dr. Graham commented on the fact that many children with useful vision, and without prognosis of deterioration of their vision, are taught Braille as a primary mode of reading. He felt that this was not the best approach. From the discussion which followed, there appeared to be a general consensus that a child should be allowed to make the maximum use of his residual vision, but in some instances additional aid such as Braille may be helpful.

Mr. Dumais stated that the blindness registers in the various States could be of material value to the Talking Book program of the Library of Congress in the Library's efforts to serve the blind population. He inquired as to whether these registers are available to the regional librarians for purpose of updating the library lists, that is the weeding out from the lists of non-active readers or those who are no longer blind. There seemed to be general agreement that this would be possible, but it was suggested, in turn, that it would be similarly helpful for the registers to have access to the list of readers from the librarians. Mr. Goldberg stated that communication of this sort undoubtedly exists in some States which use the Talking Book program as a means for updating the register. Mr. Dumais suggested that increased communication between the librarians and the State registers would be helpful in bringing both the register and the reader lists up to date.

b. TABULATION PLANS FOR 1965 AND SUBSEQUENT YEARS

Irving D. Goldberg, Assistant Chief, Biometrics Branch, NINDB.

Mr. Goldberg commented briefly on the 1964 tabulations, noting that for the first time these tables were prepared centrally by the Biometrics Branch from punch cards submitted by the various States according to specific editing instructions. The States whose registers were not on machine punch card systems submitted the required tabulations in lieu of the punch cards. This represented the first time a centralized machine tabulation effort was attempted in the MRA and it proved highly successful. It is hoped that further improvements and refinements will be accomplished with progress over the years. In this regard, Mr. Goldberg noted that it is planned to revise, and possibly simplify, the State editing procedures periodically. The cooperation of the member States in preparing their punch cards according to the directions of the Branch, editing the punch cards, and submitting them to the Branch on time, all contributed to the success achieved in preparing the tabulations in error-free form according to schedule. The procedures which were established enabled the Biometrics Branch to send to the States machine tabulations pertaining to each State's own data with minimal delay. Appreciation was also expressed for the efforts made in some of the States to reduce the number of instances of "unknowns" for various required items, thereby giving greater meaning to the tabulated data.

With regard to plans for future years, Mr. Goldberg noted that one of the aims of the Biometrics Branch was to prepare detailed tables from time to time over and above those routinely prepared each year. These so-called cyclical tables would include, for example, information in finer detail by age, specific race, detailed cause of blindness, etc., along with cross-classifications of the data according to various characteristics. The virtual universal use of punch cards in the MRA program gives greater flexibility to the tabulation plans, making it possible for the Biometrics Branch to prepare such detailed tabulations without additional burdens to the States.

The tabulation plans for 1965 are similar to the tabulation requirements for 1964. However, it is also planned to add to these some tabulations with finer breakdowns for such characteristics as age, race, and causes of blindness, both for additions during the year and total persons on the register at the end of the year. These tabulations will be prepared centrally by the Biometrics Branch from the punch cards to be submitted by the various States. One State (Massachusetts) which may not be on machine punch cards by the end of 1965 will be asked to submit tabulations similar to those prepared for 1964 and, consequently, its data will not be able to be included in the more detailed tabulations unless it can feasibly prepare the detailed data.

According to the basic plan, the detailed and special cyclical tables will be prepared for each of three years around the census (such as 1969, 1970, and 1971) and the mid-intercensal period (such as 1965). This will make it possible to provide information of a detailed nature on trends, avoiding gaps as long as ten years. Unfortunately, detailed population statistics become available only during the census years, so that adequate population data for 1965 will not be available until after the 1970 census when sufficiently detailed estimates for 1965 will be made along with those for other years in the 1960-1970 decade.

One of the items which the Biometrics Branch intends to tabulate, which has not heretofore been done, is county of residence, in order to obtain for each of the States some indication of the intra-State geographic distribution of register additions and end-of-year register totals. The absence of adequate population data for 1965 by county within each of the States will not permit the Biometrics Branch to make a complete analysis; but it will at least be possible to prepare proportionate statistics on a percentage basis. After the population census of 1970 is completed and detailed population estimates for each year in the 1960 decade become available, it will be possible to go back in time and prepare such data as rates on a county basis, along with a wide variety of other blindness statistics including trends over the years.

DISCUSSION

Mr. McCollam noted that data by county would not have much meaning in such States as Connecticut which does not use the county system. Mr. Goldberg clarified this matter, pointing out that the term "county" was used loosely to indicate a meaningful geographic subdivision of the State. In the New England States, like Connecticut and Massachusetts, where tabulations by towns would provide more meaningful information, the tabulations will be prepared on that basis rather than by county. Thus, the codes used in each State to identify the various geographic subdivisions will be employed in the most meaningful manner for the production of these geographic type tabulations.

X. OTHER BUSINESS

Dr. Goldstein mentioned that there had been some discussion as to the desirability of continuing to have annual meetings as compared to having a meeting once every two years. This discussion was stimulated by the recent budget cut sustained by the Biometrics Branch, NINDB, which made it necessary to limit attendance from each State at the present Conference to one participant (director) for whom travel and per diem would be paid by the Branch. At previous Conferences it had been possible to fund with Federal money the participation of two representatives (director and registrar) from each State. Assuming that the budget will not permit two participants from each State in the future, would it be best to have annual meetings with directors present or meetings every two years with directors and their registrars present?

Discussion that took place on this point indicated a general consensus for annual meetings over the next several years rather than biennial meetings. Representatives of several of the States indicated that they thought it possible that attendance at such meetings by their registrars might be financed by their own State budgets. This would, of course, be in addition to attendance by directors at Federal expense. A suggestion was made that, when the meetings are held in Bethesda, Maryland, an attempt be made to have them occur at about the time of the State director's spring meeting at the Vocational Rehabilitation Administration in Washington, D. C. Although attendance at the latter meeting is financed by each State, it would preclude the necessity for the director to make two trips to the Washington, D. C. area.

The question was raised by Dr. Goldstein concerning the site of next year's conference. After some discussion, the MRA member States voted unanimously to hold it in Boston, Massachusetts.

Dr. Goldstein stated that the Planning Group of the Model Reporting Area for Blindness Statistics, consisting of Dr. Ralph G. Hurlin and Mrs. Elizabeth M. Hatfield representing the National Society for the Prevention of Blindness, Dr. Milton D. Graham, Dr. Eric Josephson, and Mr. Richard E. Onken, representing the American Foundation for the Blind, Mr. Quentin R. Remein representing the Division of Chronic Diseases, PHS, and Mr. George F. Meyer, representing the MRA member States, had been exceedingly helpful in guiding the development of the Model Reporting Area. However, in view of the fact that the MRA was now a lusty, growing youngster, it was believed that the Planning Group should be replaced by an MRA Advisory Group with more representation from the MRA States, but with some from the National Society and from the American Foundation. He proposed that such Group be established by the present Conference with three MRA State representatives, one each from the National Society and the American Foundation, and two members from the Biometrics Branch, NINDB. He further proposed that, in order to provide for continuity of State representation, one of the three MRA representatives be for a term of two years, and the other two for one year. This would mean that at next year's meeting two representatives will be appointed to replace those selected at the present meeting for one year. Of the two to be selected at the next annual meeting, one would be for one year and the other for two years. This would make for continuity because in any MRA Advisory Group there would always be somebody who had been part of the previous Advisory Group. As problems arose that needed resolution by such a Group, it would be called together or contacted by mail depending upon the urgency of the problems involved. Furthermore, a sub-group of the Advisory Group, with the assistance of the Biometrics Branch, NINDB, may be charged with the responsibility of developing the agenda of the MRA conferences.

After some discussion as to the functions of such Group, a motion was made and seconded that such MRA Advisory Group be established to replace the Planning Group. The MRA member States selected Mr. McCollam of Connecticut for a two-year term and Mr. Kohn of New Jersey and Miss Anderson of North Carolina each for a one-year term.

Dr. Goldstein mentioned that during the past year the American Academy of Ophthalmology and Otolaryngology had officially endorsed the Model Reporting Area for Blindness Statistics and has urged all ophthalmologists to report to the respective registers. Also, he noted that the Section on Ophthalmology of the American Medical Association will consider the endorsement of the MRA at its next annual meeting. These endorsements are in addition to those in previous years by the Council of State Directors of Vocational Rehabilitation and the American Optometric Association.

Dr. Goldstein indicated that he would refer Dr. Graham's recommendations concerning the collection of certain socio-economic data on each blind person registered to the attention of the newly constituted MRA Advisory Group in order to get the opinions of this Group and any suggestions on implementing the recommendations.

In conclusion, Dr. Goldstein invited comments from participants on how to improve the meetings and suggestions for inclusion in next year's agenda.

The Conference adjourned at 12:20 p.m. on May 21, 1965.

APPENDIX A

The Importance of Socio-Economic Data for the Model Reporting Area for Blindness Statistics

Milton D. Graham, Ph.D.[1]

The Model Reporting Area for Blindness Statistics is really five years old today. Although this is the Fourth Annual Conference, more than a year went into the preparation of the first meeting. Looking back over those five years, one can find in the documents, correspondence and discussion two predominant themes: first, the need for standard definitions for uniform reporting and second, the need for certain kinds of data on blindness and severe visual impairment. Five years later the first theme is past discussion; it has become the basic condition of membership in the MRA.

Five years later the second major concern is only partially realized. A document of the Biometrics Branch, NINDB, dated October 2, 1961, lists two kinds of data for meeting standards of admission to the MRA: the "must" items and the "recommended" items. The "must" items are the now very familiar ones with which you deal in your annual reports, data concerning some measurements of vision and some items of registry bookkeeping.

The "recommended" items are largely socio-economic data. At your first annual meeting on March 26, 1962, the Executive Director of AFB, Mr. M. Robert Barnett, made a plea for inclusion of such data and questioned whether a State register would be useful or meaningful for research and services programming without such data. Mr. Irving Goldberg of the Biometrics Branch, in that same 1962 meeting commented on Mr. Mungovan's (of Massachusetts) remarks about the value of socio-economic data for State administrative and service planning needs. In previous and subsequent meetings I have done the same and I repeat myself again today.

The situation seems clearer to me than ever before: (1) at both State and national levels we need socio-economic data on blindness and severe visual impairment at the very least, and, hopefully in time, on less severe visual impairment; and (2) today as a result of five years research on various problem areas, we can be considerably more specific in suggesting what socio-economic data would be most useful. To develop the first point: What are the estimates of visual impairment? Without getting bogged down in definitions, the general dimensions of the problem are suggested by the Duane Report (*1*) of last year (sometimes called the Flexner Report on Ophthalmology):

> 90 million persons in the United States have some ocular malfunction. 3½ million have some permanent non-correctible defect. One million are functionally blind, unable to read newspaper type even with the aid of glasses. 30,000 Americans lose their sight each year. (p. 19)

The report continues that 80 percent of all losses of vision are caused by disease (p. 19), and more to the point of our concern here, "8 out of 10 cases of blindness are the results of diseases whose causes are unknown to science." (p. 30)

In the face of such conditions it is clear that the cause of increased ophthalmic research has great need of the present MRA data to demonstrate beyond doubt the national need to meet more decisively the challenge of blinding eye diseases. Indeed the report says of MRA: "The goal of this study is highly commendable and should be pushed to conclusion without delay." (p. 30)

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[1] Director, Department of Research, American Foundation for the Blind.

This tribute to MRA is gratifying to all of us who have watched its progress from the beginning. Your work has served to strengthen an authoritative appeal at the national level for a more intensive and rational approach to coping with our nation's blinding eye diseases. The extension of your present efforts into selected socio-economic data would facilitate at national and State levels the alleviation—if not the solution—of well-recognized problems that blind and severely visually impaired people meet. Let me give you some examples from some of the research that I know about.

Looking first to our knowledge about preschool children, we suspect that simple incidence figures—much less psychosocial data so necessary for treatment—are either inadquate or entirely lacking in most of the States of the Union. In an intensive survey (*2*) in 1963 of a local area (Los Angeles) by Dr. Arthur N. Parmelee of the Department of Pediatrics, UCLA School of Medicine, 726 blind and severely visually impaired children were identified and data collected on age, cause of visual impairment, degree of vision, and age at onset. Of preschool children, Dr. Parmelee reports:

> Our best information relative to preschool children came from the State Services for the Preschool Blind of the Board of Education of the State of California. Unfortunately only a portion of the preschool blind are referred to this service. There was no other good source of information concerning these young blind children.

Then, almost as a reminder to himself, Dr. Parmelee continues: "The ophthalmologists and ophthalmology clinics were not surveyed in this study."

Consider these points raised by this survey: (1) most blind and severely visually impaired children become so in the first year of their life; (2) medical and psychological problems left unattended for very long greatly complicate the treatment and services needed later; and (3) we need at every level (local, State, national) some standard procedure for identifying these children as early as possible.

I ask you here today to strengthen your own statistical programs in the MRA by making sure that special efforts to collect data on preschool children are made—at least the "must" data of your present requirements. Birth clinics, ophthalmologists, pediatricians, public health nurses, social workers are all possible sources of information.

School age children are more easily identified and are probably better represented in your reports, *provided they are in a school of some sort.* I stress *provided* because we know that many blind and severely visually impaired children are not in schools. In an equally intensive Statewide survey of a non-MRA State the results are even more startling. The California State Department of Public Health in 1964 (*3*) surveyed all of the known sources of records on which blind and severely visually impaired children might be listed—the number of sources was 19—and identified 3,129 blind children up to age 18. Of this number, records were explicit that 1,417 children had additional impairments of which 1,045 were classed as mentally retarded and 342 neurologically damaged. The implications to medical and social services programs of having these children identified as having other known impairments are plain enough. But more startling in this survey were the figures on where the children were: 1,842 were in public schools and presumably living at home, 170 were in private and residential schools, probably living away from home most or all of the time, and 151 were in unstated locations. Then come the startling figures: 146 were at home presumably in no school or institution, 32 were awaiting admission to an institution or hospital, and 781 were in mental institutions in which little more than custodial care can be provided. In a State known for its excellent health, education and welfare programs, *one out of four blind children are receiving custodial care only.* This survey has served to alert California to a condition that was not previously recognized and about which plans are afoot to remedy. You might do the same for your State if you add two additional items, one about other physical impairments and one other on residence. These items of information, it must be stressed, will be significant only if *all* the known sources of records are checked, not just the educational records, if California's experience is any guide. Then you locally or Statewide, and some of us nationally, will begin to know the dimensions of the much discussed problem of the multiply handicapped child (particularly the blind so-called "retarded" child), where he is and what needs to be done for him.

Statistics are not dry, unimaginative figures—particularly if you are not involved in the arduous task of collecting and tabulating them. Take, for instance, some tabulations we at AFB have compiled from a survey concerned with educational materials for blind and partially sighted children in 560 public day school systems, 44 residential schools and 30 other special day schools. Involved are 634 schools or school systems and 13,491 students, most of whom are registered with the American Printing House for the Blind for the education materials they provide. Their degree of near vision—which should logically determine their *principal* mode of reading—is reported on no standard forms and especially no prognosis of eye condition (such as the MRA form has) is made. There is evidence from the data of this survey and other surveys that there is considerable confusion about the concept of useful sight for specific purposes—that is, in this case, useful for reading after all possible visual aids and training to use those aids are considered. This becomes a crucial issue to all schools having severely visually impaired students—and that means all 634 schools or school systems in the study I am reporting on—because educational texts in braille can be changed with less speed than texts in ordinary print, given our present technology in producing braille texts. This is particularly true in public day schools where texts change frequently and the need for new texts is greatest, as our study shows. The student relying on braille is at a distinct disadvantage; he cannot keep up with his sighted peers if he reads only braille, since braille texts take longer to produce by any of the available means of production than inkprint editions. Ignoring many of the complex issues of the educational programs for severely visually impaired children — I am exempting totally blind children from discussion; they cannot use print—I submit that the realities of the situation are that children with any useful sight should be taught to exercise that sight as a primary mode of learning if they are to keep up with their fully sighted peers; the alternative is to fall behind their sighted peers because texts are not available at the time they are needed for instruction. This situation, where it exists, needs to be reported. If the educational reporting systems use greatly varying methods of measuring useful vision—as they do—I would hope that in addition to standard reporting on vision of children, an added item of primary mode of learning might be collected by MRA; such statistics might well alert State and local educational systems to the need of making methods of instruction compatible with degree of corrected vision. If, as the study on educational materials and a previous study of 1960 by Mr. John W. Jones of the U.S. Office of Education (4) suggest, too many partially-sighted children with no prognosis of further loss of vision are being taught braille as their primary mode of learning to their own educational disadvantage, then some standard system of reporting needs to point out the facts. Educational reporting systems have made little effort to require uniform reporting procedures, especially vision reports; I am suggesting that with the addition of one item—the primary mode of learning of a school-age child—the MRA which has standard vision reports can point up the problem for local and State educational authorities. The responsibility of exploring the implications of such statistics is truly educational. But the collection of statistics on the use of partial vision is not contrary to MRA objectives, as I see them.

Equally within the mission of the Model Reporting Area—as has been repeatedly suggested from the first meetings in 1961 and 1962—are statistics on the *principal* mobility mode of blind and severely visually impaired persons. It is generally accepted opinion that blindness and severe visual impairment impose two severe handicaps: access to the printed word without other human intervention and the ability to get around (that is, mobility) without the help of another person. Our sketchy research data confirm these two common-sense observations. But we lack any dramatic proof that mobility is anything more than a desirable thing because people in general like to get about when they please and without having to depend on someone else. I say that it is more than *desirable* for a blind or severely visually impaired person to be mobile. It directly affects his earning capacity if he or she is of employable age and is considered in the labor force.

Consider this case. The first 100 of 853 blinded war veterans were studied last year for their mobility patterns (*5*), that is, how active are they, how do they get around and what effect, if any, does a mobility pattern have on family status, income and the like. Without burdening you with details, a rating scale of activity was drawn up and each of the 100 veterans rated. Then the 25 least active (low scorers) were compared with the 25 most active (high scorers). On principal mode of travel, 20 percent of the low activity group use their vision for travel only occasionally, not regularly, while 40 percent of the high activity group use their travel vision regularly. More important is that 48 percent of the low activity group have no useful vision —are blind—while 60 percent of the high activity group are totally blind. So what aids do they use principally? Very few use guide dogs or electronic devices. Low activity veterans use a variety of canes and receive no training in their use; 40 percent of the high activity group use the typhlocane, or to use its other names, the Hoover cane or long cane, with which they have received rigorous training. What differences follow from these mobility patterns? Two mainly. One is that 60 percent of the low activity veterans are not in the labor force while 16 percent of the high activity veterans and 20 percent of the long cane users are not in the labor force. The second is the related figure of household income. The average income for 1963 for the U.S. was $6,200, for college graduates $9,700. The average income for low activity veterans was $7,435, for high activity veterans $11,540, for long cane users $11,500.

The implications seem clear enough. There *is* a relationship between mobility training and employment and income. What blind people of working age may really mean when they say getting around is their major problem—and this is most frequently mentioned in several surveys—is that decreased mobility means less work and less income, and conversely more dependence on others.

How can you in MRA help us tackle this complex problem? If you provided data on principal mode of travel and income, some of us could undertake more meaningful research and others could better plan services, like mobility training programs.

My final two examples of research reports that suggest valuable socio-economic data needed for research and program planning purposes concern the blind and severely visually impaired population aged 50 and over, which accounts for more than half of the blind population. Consider the plight of the aged blind. We know that 80 percent of all vision loss is due to disease: then at age 50, or thereabout, his vision impairment becomes serious enough to affect his functioning as usual; at the same time his general health, his earning power and probably his social activities are waning. Under these conditions, the newly blind and aging person undoubtedly suffers trauma that may be severe.

From our research we know that misery comes in large packages to some people, like the multiply handicapped blind child whose remaining senses are not sufficiently stimulated and he is diagnosed as retarded, is institutionalized, and becomes forever emotionally deprived. The other example that comes to mind are those aged blind with other impairments, with poor mobility patterns, that is, the isolates or "rocking chair" cases, and finally to compound the misery, they receive only enough cash income to keep them at a subsistence level, if that.

For instance, some of the characteristics of recipients of Aid to the Blind as set forth in a recent survey (*6*) of 85,521 recipients by the Bureau of Family Services, U.S. Welfare Administration: only 25 percent were under 50 years of age; 42 percent of them live in other people's homes or in institutions; 18 percent, or about 16,000 of them live alone; only 10.6 percent have talking book machines for recreational reading; only 8.6 percent read braille; 62 percent of them never were referred to vocational rehabilitation services; 16 percent never travel from home while an additional 40 percent travel only on somebody's arm; 36 percent travel alone, 13 percent using a cane; they receive an average of $93.82 per month and 26.5 percent, or about 23,000, have unmet needs financially by even the standards of the Welfare Administration.

It seems clear that many of these aged persons are within the definition of poverty as defined by the U.S. Office of Economic Opportunity, and for whom something might be done by that agency, if we could identify them. Certainly those persons over 50, with other known impairments, living alone, having poor mobility patterns (home-bound or exclusively dependent on others for travel), and having less than $3,000 total cash income per year bear investigation as possibly poverty cases. (This may not always be so, however, as a study of 100 rural blind persons in Utah (*7*) pointed out: with an average income of $1,685 only five were considered by social worker interviewers to have unmet needs.)

What poverty or isolation means is made quite clear in another study of 157 persons reported to be blind from senile cataracts in New York City (*8*). Seventy-one, or roughly half of them had a medical prognosis of treatable, and 31 uncertain. With cataract surgery, 90 percent or more effective these days, probably one-half to two-thirds of the group could have had their vision restored by cataract surgery had they submitted to surgery, which they were encouraged to do by counselors. Only 45 percent, or 70 persons, did undergo surgery. Why so few? There are several reasons, of course, but the author says of his study:

> Perhaps the most important thing which emerges from these data is the picture of deprivation which is reinforced by the fact that more than half of the total group live alone and isolated. (p. 70)

Where the family was supportive, they encouraged surgery.

Again, as with children, if we knew their living conditions, we might identify more quickly those in dire need and those who might be convinced, through intensive public education programs and counseling programs, to take remedial action.

These are only a few of the situations that occur to me, situations in which the problems of blind and severely visually impaired persons might be more readily identified if MRA carried certain items of socio-economic data. To sum up for you, the situations outlined above would involve adding the following items: (1) for children: their residence (home, institutionalized, etc.), near vision measurement, and primary mode of reading (sight, braille, etc.); (2) for working age adults: principal mode of mobility (sight, guide dog, long cane, etc.), income and residence; (3) for aged adults: living arrangements (own home, roomer, alone, etc.), income, principal mode of mobility, and other physical impairments.

This is nothing like a final list of needed socio-economic data. These are only illustrations of cases where such data would be most useful to research and program planning. Of course, there would be many difficulties in collecting such data, like the need for standard definitions for uniform reporting and the like.

Such problems are not insuperable. You established your present uniform reporting procedures through conferences, workshops and annual meetings such as this one. The structure exists for adding socio-economic data. It should be used.

In closing, I would like to end on a note of urgency. The numbers of blind and severely visually impaired persons is increasing, not decreasing, as we sometimes hear. Listen to two authoritative voices. The Duane Report (*1*) attacks head-on the myth that with coming advances in medical science blindness and severe visual impairment will become negligible in the U.S. I repeat one quotation from the report: "Eight out of ten cases of blindness are the results of diseases whose causes are unknown to science." (p. 30) And add this quotation:

> It is true that advances have been made in the development of diagnostic and treatment techniques, and that early detection, diagnosis and treatment of diseases can substantially reduce the incidence of blindness. These techniques can be further improved through research. But it is a long step from the recognition of a disease to an understanding of its causes. Dr. Norman A. Ashton, a world-renowned eye pathologist of London, recently stated that every operation for cataract or retinal detachment is an admission of defeat and ignorance, because it merely indicates that we have been unable to deal with the causes. (p. 30)

A research ophthalmologist dealing mostly with eye diseases of children, made these remarks (*9*) during a conference in March 1965:

> . . . somewhere between three-fifths and two-thirds of blindness in preschool children is prenatal in origin . . . retrolental fibroplasia can be considered postnatal . . . I think this prenatal proportion will continuously rise . . . There will be better obstetrical care so that there will be more premature children surviving . . . There will be a decline in other postnatal causes, like RLF, but there will be a total increase in the number of people born. All of these conditions will continue to supply a large blind population, probably consisting more and more of people with congenitally prenatally established causes.

There are going to be more blind and severely visually impaired people as time goes on, especially since we are saving more premature babies who are more prone to neurological conditions (including blindness) and at the same time we are increasing the longevity of our population. This increased blind and severely visually impaired population is going to have some of the problems that I have outlined a few minutes ago, and many more. What to do about it? There is a general trend toward the intensive study of perinatal influences, of mental retardation, of aging, of poverty — all general studies which directly bear on the problems of our population who are blind and severely visually impaired. Let us join these studies. Give us in research the necessary statistical base to know where to start, what problems are most pressing, and so forth. Give the program planners similar statistics so that they can strengthen some programs and initiate others.

I repeat my plea of 1960 and every year since: let MRA give us the socio-economic data that we need. It is important that we have it—and have it as soon as possible.

DISCUSSION

Mr. Kohn stated that he felt Dr. Graham's presentation was a very perceptive statement as to the needs for certain basic socio-economic data necessary for program planning and that Dr. Graham's request for such data should be supported. It was Mr. Kohn's opinion that the nature of programs of service to blind people was undergoing change and, therefore, the collection of such statistics was of primary importance for purposes of blindness prevention and for long-range program planning to meet the needs of persons who might become blind. Dr. Goldstein pointed out that he had been convinced for some time that good statistics and good services for the blind go hand in hand.

In agreeing with Mr. Kohn, Mr. Gambaro indicated that Dr. Graham's presentation had provided the impetus needed for his agency to continue the difficult task of collecting basic socio-economic data. Mr. Gambaro noted that in developing the District of Columbia register, he was having difficulty collecting certain socio-economic data and that he had been undecided whether or not the merits of socio-economic data warranted the extra work necessary to collect such information. However, Dr. Graham had convinced him that the benefits of having good socio-economic data available would justify the amount of work necessary to obtain it.

Mr. Mungovan questioned Dr. Graham as to the possibility of obtaining the socio-economic data through sampling procedures in a State, rather than obtaining such data continuously from the whole State register. Dr. Graham thought this might be a practical approach. Mr. Goldberg commented that one of the objectives of the Model Reporting Area program is to conduct research studies on blindness, using registers of the blind, and that two such studies (based essentially on a sampling of the registers) have already been conducted very effectively. He pointed out that such socio-economic data as that under discussion could be collected by the States either on a continuing basis, on a total register basis for a single year, or on a sample basis. If not on a continuous basis, he suggested that the survey or sample be repeated periodically in order to obtain any evidence of changes over a period of time. Mr. Goldberg stressed that the Biometrics Branch would be happy to entertain this type of research effort and to participate in it.

Mr. Goldberg noted that where States have desired to collect socio-economic data, the Biometrics Branch has recommended uniform codes for such data so that there will be uniform statistics from State to State. He pointed out that some of the Model Reporting Area States already collect information on such items as mobility, other impairments or handicaps, marital status, education, occupational status, and hearing impairment. Although consideration will have to be given to the source, reliability and validity of the information collected, Mr. Goldberg stated that there is a great deal of uniformity among these States in their classification of such data.

A question relating to statistics quoted in the Duane Report, led to a great deal of discussion regarding the wide use of erroneous or unreliable statistics relating to the incidence, prevalence, and trend of blindness. Not only is it difficult to pin down the sources of these various unreliable estimates, but different sources are given for such data. In commenting on this problem, Mrs. Hatfield emphasized that the use of various erroneous data leads to great confusion and results in the production of misleading information. Since the MRA is not yet able to produce national estimates, the National Society for the Prevention of Blindness hopes soon to publish a pamphlet on blindness statistics which may help to resolve at least part of the problem. Mr. Burns commented on some of the reasons for the confusing statistics which are used and, pointing to the lack of valid statistics over a period of time, he emphasized the need for the kinds of statistics which the MRA is attempting to produce as well as the importance of collecting the type of information proposed by Dr. Graham. Through such efforts he hoped that much could be accomplished towards prevention of blindness. Mr. Goldberg stressed the importance of using caution in quotation of blindness statistics until such time as reliable and valid data become available. Thus, he noted how the readers of the MRA statistical reports are cautioned not to project the MRA data to the country as a whole. Hopefully, the Model Reporting Area will soon be able to make such national estimates.

In view of the fact that Dr. Graham's presentation generated considerable enthusiasm among the conferees, Dr. Goldstein asked for and obtained the conferees' approval to refer Dr. Graham's recommendations to the newly constituted MRA Advisory Group. The Advisory Group will be asked to offer their suggestions and recommendations as to how the inclusion of socio-economic data might best be implemented within the Model Reporting Area.

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APPENDIX B

Causes of Blindness in Canada:

An Analysis of 24,605 Cases Registered with the Canadian National Institute for the Blind [1]

Alexander E. MacDonald, M.D.[2]

Canada has been fortunate in that there are available records of eye examinations of blind people in all parts of the country that have been collected under one roof. Since 1918 these records of the Canadian National Institute for the Blind (CNIB) have been assessed and categorized, and are kept up to date in one central file in Toronto.

In Canada the definition of blindness (as amended by the Federal Order in Council on July 25, 1962) reads as follows: "A person is considered blind if the visual acuity in both eyes with proper refractive lenses is 20/200 (6/60) or less with the Snellen chart or equivalent, or if the greatest diameter of the visual field of both eyes is less than 20 degrees."

This 1962 standard is used by the Blindness Control Section of the Department of National Health and Welfare to administer the payment of assistance, and independently by the CNIB in registration of blind persons. For the purposes of coding, blindness in an individual is determined for the better of the two eyes for vision and field.

The present survey was the third such conducted in Canada and differed from the preceding surveys in 1946 and 1954 in that each patient's history was studied by the consulting ophthalmologist who was responsible for the cross-classification of topography (site and type) and etiology (primary cause of blindness). With respect to trauma as a cause of blindness, a supplementary code indicated the individual's activity at the time of injury. This survey is probably the first to include blind persons of all ages in one nation in a punch card file that will be continued indefinitely.

This survey is based on an analysis of the records of those persons registered as blind with the CNIB. It is not a national survey of all blind persons in Canada, and it should be noted that registration of blindness is not mandatory in Canada. The CNIB registry is not of all blind persons, but it is the most comprehensive if its kind in Canada.

The directors of the CNIB authorized this third survey because of the steady increase in the number of registered blind persons. Medical advances in the treatment of serious ocular conditions and active preventive work have not halted this increase. The individual punch cards prepared for every person registered with the CNIB as blind contain much information beyond the ophthalmic codification, such as the blind person's status, place of residence, services needed, etc., which would be useful to those responsible for the administration and integration of the work of some 50 branches of the CNIB.

The preliminary report of the major causes of blindness that is recorded here is based on the records of 24,671 people of all ages—the living CNIB registered blind persons in this country. The reports of eye examinations carried out on each of the 12,680 males (51.4 percent) and 11,991 females (48.6 percent) in this group are deposited centrally at Toronto, and these reports were coded prior to the preparation of individual punch cards.

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[1] Condensed from paper by Dr. A. E. MacDonald published in the Canadian Medical Association Journal, 92, 264–279, 1965.

[2] Consultant (Ophthalmologist), the Canadian National Institute for the Blind.

Table I shows the age-distribution of these 24,671 blind persons. It should be noted that some 54 percent of the registered blind are under 65 years of age whereas some 46 percent are over that age.

Age in years, at the time of registration, for the major causes of blindness in Canada is shown in Table II. It should be noted that this table includes those individuals with known age at the time of registration. Please note that, with the exception of macular degeneration, multiple anomalies, and detached retina, the greatest number of patients were registered when they were between the ages of 19 and 64 in every cause category listed in the table.

Codification for topography (site and type of lesion causing blindness) and etiology was the responsibility of the consulting ophthalmologist who examined each individual's record which often included reports of many examinations. This survey was begun late in 1959, using some modifications to include causes for blindness that had been omitted from the 1957 National Society for the Prevention of Blindness (NSPB) cross-classification. Some of these are amblyopia, sympathetic ophthalmia and those surgical procedures for cataracts in which, after operation, the patient had remained in the blind group or was later returned to it. The CNIB consultant recorded the patient's age at the time of ocular involvement, but the presence of similar familial visual defects, if other close relatives were affected, was indicated by the registrar.

The coding used in this survey reports the age at onset of blindness, to distinguish between prenatal and postnatal causes in recording blindness due to toxoplasmosis and histoplasmosis, infection, gonorrhea, syphilis, ulceration and phthisis, cataracts, trauma, and retrobulbar disease. For many of these diseases the onset of the condition may precede, sometimes by years, the time of registration, as in retinitis pigmentosa which is a genetic defect.

As indicated above, the 1957 cross-classification of the NSPB in the United States was used.

This national survey of blindness in Canada, based on CNIB data, ended on March 31, 1963, and used the estimate of the National Bureau of Statistics for the population of Canada as 18,913,000.

In this temperate-zone nation that extends from its southern boundary to three oceans, the CNIB prevalence of blindness by province varies from a low of 108 per 100,000 to 376 per 100,000. In 1946 Aylesworth obtained a prevalence of blindness of 105 per 100,000 population and in 1954 MacDonald noted that this CNIB figure had increased to 127. The present survey shows a further increase to 131 per 100,000 for the 24,671 blind persons. It should be noted, however, that the study only includes reports on 24,605 persons because the survey ended just before the CNIB Annual Report of March 31, 1963.

Causes of Blindness by Site and Type

Cataract, one of the major causes of blindness, accounted for 3,723 cases or over 15 percent of the total. Of the total number of cataract cases about 36 percent were established as or presumed to be due to prenatal influence. Other causes were diabetes, accounting for about six percent and traumatic lesions for about two percent of the cataract cases.

Glaucoma, excluding the infantile congenital type, accounted for ten percent of the blindness in the registered group or 2,384 cases. There was evidence of a familial tendency to glaucoma in 187 patients or about eight percent of these cases. Among those with glaucoma, there were 22 diabetics. With respect to cause, the remaining cases were classified as "unknown to science." Various other known causes not elsewhere classified accounted for about 1.5 percent of the cases. Vision was nil or reduced to light perception in almost one-third of the individuals, a little over one-third had 3/60 (10/200) vision or less, and slightly less than one-quarter of the cases had less than 6/60 (20/200). A limited field of vision led to the registration of about 12 percent of the cases with glaucoma. These individuals, of course, had vision which was better than 6/60.

Malignant myopia was the major cause of blindness in 2,232 cases or about nine percent of the total group in the study. The vision in about five percent of these persons was nil or reduced to light perception only; it was 3/60 or less in almost half the cases and 6/60 or less in almost half. Prenatal and familial influences were noted in the blindness of slightly over a third in the myopia group.

Retinal pathology accounted for 5,563 cases or 23 percent of the blindness in this survey. Specific retinopathies and retinitis represented a little less than a quarter of this total; of these about 55 percent were diabetic and 30 percent were vascular. Macular degeneration, accounting for almost a quarter of the cases with retinal disease (1,318 cases), was followed in order of frequency by retinitis pigmentosa with 1,292 cases. Retinal detachment (437 cases) was more frequent than retrolental fibroplasia (336 cases). Among those with blindness due to disorders affecting the retina, almost a third were considered to be due to familial and prenatal causes.

Corneal lesions caused blindness in 1,456 persons or six percent of the entire group. Interstitial keratitis was the major cause of blindness due to corneal disease and accounted for about one-fifth of such cases (295 cases).

About 6.5 percent (1,634 cases) of all the blind in this study were registered with some form of uveal pathology. Of these iridocyclitis and uveitis accounted for 646 cases and chorioretinitis for 457 cases.

The optic nerve and central nervous system were involved in 10.5 percent (2,556 cases) of those registered with the CNIB as blind. Atrophy of the optic nerve was present in 1,398 cases while retrobulbar and intracranial lesions numbered 956.

About 0.5 percent (123 cases) were diagnosed as having vitreous hemorrhage.

Only 0.5 percent (121 cases) of all the registered blind were recorded under "site not specified" or ill-defined.

Causes of Blindness by Etiology

Analysis of the etiology of the cases in the study indicated that the diseases listed in the 1957 NSPB Classification as "infections specified" and "infections not specified" accounted for about 12 percent (3,065 cases) of the study group.

Another cause, syphilis, was responsible for less than three percent or 672 cases in the study. Ophthalmologists of long experience do not now find syphilis to be a common cause of blindness.

Individuals with traumatic blindness included 1,339 cases or five percent of the total number.

There were 441 cases of these under "poisonings;" 329 were cases of retrolental fibroplasia. Most of these occurred before the specific cause, oxygen poisoning, was found; now it occurs only sporadically in premature low-weight incubator babies.

Neoplasms were responsible for 355 cases or 1.5 percent of the blind group, including 11 cases in which the type of the tumor was not specified. Classified under specified types, 286 cases were due to intracranial tumors. Surgical intervention in this field is now so much more successful that many more patients survive. Fifty-two cases of blindness were due to retinoblastoma and six to malignant melanoma.

Diseases not elsewhere classified constituted about 12 percent (3,831 cases) of the total group. Among other diseases, it included diabetes, vascular diseases, etc. It was noted that diabetes as a cause of blindness was on the increase, associated with retinal lesions and hemorrhages into the vitreous. This impression has been confirmed by the finding of 1,238 diabetic subjects or five percent among those registered as blind in the present survey. In a previous survey in 1954 there were only 636 diabetic subjects in a group of 18,998. Vascular pathology in this survey accounted for 4.5 percent (1,167 cases) of all registered blindness.

The causes of the innumerable variations in the rate of senescence and degeneration in man are not yet known and, as is the custom, senescence and degeneration are classified in this study as disorders for which the cause is "unknown to science." Cataracts and glaucoma (excluding those due to congenital causes), myopia and many of the degenerations form a large proportion of the causes of blindness in the 6,451 cases with etiology "unknown to science" which account for 26 percent of the cases under study.

General Discussion

In surveys of blindness, older and younger age groups are frequently omitted. It probably also happens that overlapping of populations or causes occur. Census reports for blindness have been found to be unreliable and, in Canada, actual registration of blind persons gave an estimate that was double that of the corresponding census estimation.

The matter of international comparison deserves special comment. The standard adopted by the CNIB in Canada for the assessment of blindness as a condition of registration is more liberal than that used in many countries, and for this reason, adjustments must be made in comparing reports from other countries. The number of blind persons covered in this report (the third CNIB survey) would have been reduced by approximately 30 percent if the visual standard 3/60 (10/200) had been used. The reduction in the number of cases registered would have been most marked for myopia (1,041 less cases), cataract (1,216 less), and macular degeneration (621 less). For the age groups frequently omitted or emphasized in published reports in the past, there would be a noticeable difference. For example, excluding the age group 70 years and over would have reduced registration by approximately 37 percent. If the group "blind at birth" were excluded, the reduction would be 13 percent, and if all those under eight years of age were removed from the register, 20 percent.

The ophthalmologists of Canada, over 500 in number, have supported and cooperated in the work of the CNIB. Even before standard printed forms were adopted for recording the details of eye examination, only a few reports (0.5 percent of the total) failed to give sufficient evidence with regard to the type and site of the lesions responsible for the blindness, and in only about five percent of the records was information concerning etiology deficient.

This survey brings to light the fact that over one-third of the cases of blindness registered with the CNIB are due to prenatal causes. Of the more than 500 named congenital syndromes producing serious defects of the body, probably one-third involved the visual apparatus. Only recently, in 1960 in London, the First International Congress on Congenital Malformations, and in 1962 the First Inter-American Conference on Congenital Defects pointed out the urgency and the magnitude of the search for means of preventing congenital causes of blindness.

In the second largest group, those blind from causes "unknown to science," some reduction in incidence is possible through better nutrition, hygiene, and through new studies on the causes of premature senescence.

Table I. Age distribution of blind persons registered with the Canadian National Institute for the Blind as of March 31, 1963*

Age (in years)	No. of Cases	Percent
100 and over	13	0.06
70 to 99	9,041	36.65
65 to 69	2,329	9.44
Total 65 and over.	11,383	46.15
40 to 64	7,979	32.34
21 to 39	3,053	12.37
7 to 20	1,891	7.66
6 and under	365	1.48
Total under 65.	13,288	53.85
Grand total	24,671	100.00

* Adapted from A. E. MacDonald: Causes of Blindness in Canada. Canadian Medical Association Journal, 92, 264–279, 1965.

Conclusion

The increase of blindness in Canada, reported herein on the basis of CNIB data, may be more apparent than real and may simply reflect increased use of the many services that are available for blind persons. Even those of independent means seek help in varying degrees. Medical advances have brought many of the causes of blindness under control, and surgery restores vision even in those conditions designated as having a cause "unknown to science." However, the longer life span permits many more cases of blindness due to degenerative changes to become manifest.

The long search for national statistics on the causes of blindness still depends upon the addition of accurate and comparable reports from other countries.

Table II. Blind persons with known age registered at C.N.I.B. by major cause of blindness as of March 31, 1963*

Major Causes	Age (in years) Percent						
	No. of cases	At Birth	Beyond birth but under 9 yrs.	9-18	19-64	65-69	70+
Cataract	3,722	19.3	4.4	5.1	42.2	6.6	22.4
Glaucoma	2,384	0.3	0.0	0.4	58.2	10.0	31.1
Myopia	2,232	6.5	3.8	14.7	65.6	3.8	5.6
Retinopathy	1,460	0.3	0.4	1.6	60.9	9.1	27.6
Macular degeneration	1,307	3.7	1.8	5.2	27.1	6.7	55.5
Retinitis pigmentosa	1.292	7.6	4.2	15.8	69.5	0.7	2.2
Multiple anomalies	851	47.0	12.0	21.6	19.2	0	0.2
Detached retina	437	0.9	1.1	7.1	76.2	4.6	10.1
Total	13,685	10.4	3.2	7.6	51.6	6.0	21.2

* Adapted from A. E. MacDonald: Causes of Blindness in Canada. Canadian Medical Association Journal, 92, 264–279, 1965.

APPENDIX C

Evaluation of Visual Field Criteria in the Definition of Blindness by State Consulting Ophthalmologists

Irving D. Goldberg[1]

At the Third Annual Conference of the MRA in Raleigh last year I raised for discussion a problem concerning the interpretation of the definition of blindness. Specifically, the problem dealt with that portion of the definition relating to field of vision, namely, "visual acuity of more than 20/200 if the widest diameter of the field of vision subtends an angle no greater than 20 degrees." The question concerned itself principally with the interpretation of what constitutes a 20 degree limitation. It was apparent from the many queries received by the Biometrics Branch that there were differences of opinion as well as questions relating to this matter.

For purposes of orientation some comments should be made about the origin or basis for the current definition. As I understand it, the visual field restriction concept, as contained in the usual definition of economic blindness (which is essentially that of the MRA), had its origin around 1934 when the American Medical Association considered the definition of blindness. The results of the AMA's consideration formed the basis for the Social Security Administration's recommendation regarding a standard definition of blindness.

At the time of my presentation last year I referred to instructions prepared by the Social Security Board in 1940 which were directed to State agencies participating in the study of causes of blindness among recipients of Aid to the Blind. With regard to the category of vision "better than 20/200 with peripheral limitation indicated" the following explanation was given in the Social Security Board's instructions: "To judge the size of the peripheral field remaining, one must find the diameter in degrees across the widest portion of the visual field and note its measurement. The limits of a useful field may be symmetrical (i.e., both extremities of the widest diameter may reach an equal distance) or they may be irregular." It was this aspect of the definition which apparently required clarification.

After the subject was discussed at the last Annual Conference, it was recommended by the conferees that the Biometrics Branch, using where possible the resources of the MRA States, look into this matter so that the Model Reporting Area might arrive at a uniformly acceptable definition. Accordingly, in March of this year, the directors of blindness programs in the 17 member and nonmember States affiliated with the Model Reporting Area were requested to obtain the assistance of their consulting ophthalmologists. It is very gratifying for me to report that each of the States was most cooperative in this matter; and I wish to take this opportunity to thank each of the respondents on behalf of the Biometrics Branch and the MRA. The directors of the blindness programs in each of the 17 States received comments from one or more consulting ophthalmologists so that a total of 23 ophthalmologists participated in the inquiry. The responses were submitted to the Biometrics Branch for review.

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[1] Assistant Chief, Biometrics Branch, National Institute of Neurological Diseases and Blindness.

The attempt to arrive at a resolution of the basic problem was based on four questions directed to the consulting ophthalmologists. These were as follows:

1. How does he interpret the angle subtended in the widest diameter of remaining field of vision (e.g., in terms of diameter, radius, point of fixation, etc.)?
2. How does he apply to the definition of blindness those conditions where vision is not present in all four quadrants (such as in hemianopsia)?
3. In the examination for field of vision, what size and color of target used are acceptable, at what distance, and by what method (e.g., perimeter, tangent screen)?
4. What other specific factors are considered when determining whether a person is blind by reason of field restriction?

The extent of the problem was evident from the nature of the replies received from the various ophthalmologists. It is important to emphasize that while we have attempted to summarize the replies to the questions in simple tabular form for your information at this Conference, the apparent simplicity of these tabulations should in no way be interpreted as meaning that the resolution of the problem is a simple one. Indeed, the summary tabulations which we arrived at proved to be a most difficult task. For example, it was not possible to put into the tabulations some important subjective and conditional comments. Further, I must emphasize strongly that the data presented in the tabulations are limited and provisional in nature. Consequently, I urge you to take special note of this fact and that you consider these tabulations in light of this provisional nature. The tables were prepared for your use at this Conference to give you some idea of the results of the evaluation. In this regard, please note that the tables summarize data extracted from the ophthalmologists' correspondence by nonmedical personnel and they should be considered in this light. It is hoped that additional evaluation of the responses and a full appraisal of the problem can be further pursued by an appropriate body of ophthalmologists.

I will now briefly review with you the tabulations which were prepared.

Question 1: How does he interpret the angle subtended in the widest diameter of remaining field of vision (e.g., in terms of diameter, radius, point of fixation, etc.)?

Tables 1(a) and 1(b) summarize the responses to this question. Of the 23 replies, ten did not specify use of either of the terms "radius" or "diameter," and eight replies were nonspecific with regard to the point of fixation. Where specified, 11 of 13 respondents used a "diameter of 20 degrees," and 12 of 15 respondents stated that the point of fixation must be included. The relationship between inclusion and location of the point of fixation is shown in Table 1(b). It is clear that interpretation on this matter differs among the respondents. For example, of those who mentioned the point of fixation, opinions were equally divided as to whether the diameter (or radius) should be measured from that point (i.e., terminal point) or not.

Question 2: How does he apply to the definition of blindness those conditions where vision is not present in all four quadrants (such as in hemianopsia)?

The replies to Question 2 are summarized in Table 2. Of the 12 respondents whose comments were specific on this matter, only one indicated that hemianopsia was a sufficient criterion to classify a person as blind, and 11 took other criteria into account.

Question 3: In the examination for field of vision, what size and color of target used are acceptable, at what distance, and by what method (e.g., perimeter, tangent screen)?

The summary of responses to Question 3 are shown in Tables 3(a), 3(b), and 3(c). The method indicated (i.e., perimeter or tangent screen) is that which is used or preferred. Four replies were not specific with regard to method. From the remaining 19 replies, it is apparent that general use is made of both methods. Based on replies which were specific, there apparently is little consistency with regard to size of target used in either the perimeter or tangent screen methods. However, there was consistency with regard to color and distance of target. One respondent used a luminescent target while all others who specified color used a white target. In the ten instances where the distance was indicated among respondents using the tangent screen, all specified a distance of 1,000 mm (1 meter); and for the perimeter method, seven specified a 330 mm (⅓ meter) distance while one respondent indicated a distance of 260 mm.

Question 4: What other specific factors are considered when determining whether a person is blind by reason of field restriction?

Table 4 summarizes the replies to Question 4. Of the 17 ophthalmologists who responded specifically to this question, 9 indicated that other factors, such as muscle palsy, scotoma, etc., are considered in determining blindness for reason of field restriction.

It is interesting to note that 12 of the 23 respondents volunteered ancillary comments regarding their attitudes toward the definition or criteria for blindness based on visual field restriction. It is evident from the nature of these comments which are summarized in Table 5, that there is some interest among this group of ophthalmologists for clarification of further study of the problem.

In conclusion, there is evidently no simple solution to the questions raised by several MRA members regarding clarification of field of vision criteria for defining blindness. This matter obviously needs further study. For the present, we can only recommend that you continue to use the same guidelines which you have been using, presumably with the assistance of your consulting ophthalmologists. Insofar as the MRA can do so, it will try to pursue this matter further towards a suitable resolution of the problem.

Table 1

Summary of Responses to Question 1

(a)

	Inclusion of Point of Fixation			
Radius or Diameter	Total	Always Included	Not Necessarily Included	Not Specified
Diameter of 20°	11	8	2	1
Radius of 10°	1	1	–	–
Radius of 20°	1	1	–	–
Not Specified	10	2	1	7
Total	23	12	3	8

(b)

	Location of Point of Fixation			
Inclusion of Point of Fixation	Total	Terminal Point	Not Necessarily Terminal Point	Not Specified
Always Included	12	5	7	–
Not Necessarily Included	3	3	–	–
Not Specified	8	–	–	8
Total	23	8	7	8

Table 2

Summary of Responses to Question 2

	Total
Hemianopsia is sufficient criterion to classify person as blind	1
Hemianospia is not necessarily sufficient criterion to classify person as blind (i.e., criteria of diameter or radius of field also used)	11
Not specified	11
	23

Table 3

Summary of Responses to Question 3

(a) Size of Target

Method	Size									
	Total	1°	1 or 2 mm	2 mm	3 mm	5 mm	6 mm	10 mm	Varies	Not Specified
Perimeter	5	1	–	–	2	1	–	–	1	–
Tangent Screen	8	–	–	1	2	–	–	3	1	1
Either:	6									
Perimeter	(6)	–	–	–	1	–	1	–	3	1
Tangent Screen	(6)	–	1	–	–	–	1	–	3	1
Not Specified	4	–	–	–	–	–	–	–	–	4

(b) Color of Target

Method	Color			
	Total	White	Luminiscent	Not Specified
Perimeter	5	4	–	1
Tangent Screen	8	6	1	1
Either:	6			
Perimeter	(6)	4	–	2
Tangent Screen	(6)	4	–	2
Not Specified	4	–	–	4

(c) Distance of Target

Method	Distance in mm				
	Total	260	330	1000	Not Specified
Perimeter	5	–	4	–	1
Tangent Screen	8	–	–	6	2
Either:	6				
Perimeter	(6)	1	3	–	2
Tangent Screen	(6)	–	–	4	2
Not Specified	4	–	–	–	4

Table 4

Summary of Responses to Question 4

Other Criteria	*Total*
Other condition (e.g., muscle palsy, scotoma, functional vision, ambulation, hysteria, occupation, etc.)	8
Consideration of visual acuity and field limitation in both eyes	1
No other criteria used	8
Not specified	6
	23

Table 5

Summary of Miscellaneous Comments

Nature of Comment	*Total*
Interested in clarification or standardization of definition	4
Interested in new definition	1
Interested in further study of the problem	2
Very interested in the problem	2
Prefer some flexibility in criteria (e.g., clinical judgment)	3
No comment	11
	23

APPENDIX D

Considerations Relating to Visual Field Criteria in a Definition of Blindness

Austin Lowrey, Jr., M.D.[1]

I feel grateful to be present here with you today to discuss views and considerations that go to make up the definition of blindness. As one can judge from what has been said here today, the term blindness means many things throughout the world. In Ireland the term blindness means that you are not able to do ordinary work. In the Netherlands it means that you are not able to participate in ordinary social events. In most of the countries of the English Commonwealth 6/60 is used, which is more or less comparable to our 20/200. And so it goes. In this country we have, as you know, our more or less standard definition. In addition, we have two other levels of vision that are more or less used to denote the same thing—blindness. We have that which is taught in medical schools. Most medical schools and optometry schools mean by the term blindness that you have light perception but not projection. For pension purposes the Social Security people and the Veterans Administration use oftentimes 5/200 or a visual field of five degrees. Then of course we have the industrial definition which we are all familiar with. So then, we have here a variety of opinions on what the term blindness means around the world. We also have another situation which should be mentioned, and that is the definition for blindness that we use in that group, where 85 percent of them still have some usable vision.

This brings up the subject of what is it that we want. Do we want a definition to cover blindness and the severely visually handicapped, or do we want two definitions? First of all, we have got to determine and decide what we want to define. I feel that it can be done in a group like this, and may I at this time compliment Dr. Goldstein and this whole group here, for the great progress you have made in the Model Reporting Area for Blindness Statistics. I think it is wonderful. I am sorry that at this day and age it is just getting started, but I lay that to the fact we have had, in medicine, a hierarchical type of administration. We have had many other factors that go into the creation of the need for such a definition. In many such things as a definition of blindness you have to have the motivation of money before you can get it started and get it off the ground. I do not know whether that is part of this picture now, but I am mighty glad to see it get started and rolling.

The definition we use for blindness has been criticized by nearly every group, professional and otherwise, that we have here in the United States. I think I can be fair in saying that it is ambiguous, difficult to interpret, and that there is practically no standardization required in coming up with those two factors that go into this definition, namely vision and fields. So, we will start out now with the talk by asking whether it is fair to criticize the definition because it uses only two components of visual function or visual ability.

My answer to that question is "yes," that we need more components, more elements of the visual function to go into a definition of blindness. The present definition does not cover anyone who is color blind or anyone who has night blindness. It is entirely lacking when it comes to muscle function, or dark adaptation, or depth perception, or many of the other factors that go into the component picture of visual ability. My second recommendation would be that all these other functions of vision and visual ability should be considered and certain ones used to fit any new definition that is being considered. I would like to criticize the fact that we only use distant vision. I think that people of low visual acuity, who fall within this definition, use their close vision much more than they do distant vision. So that certainly near vision would be desirable to use in coming up with any final definition. Then, every factor that goes into taking vision in all of these various components of visual ability has to be standardized and spelled out. We know that there are some 25 factors that go into just taking visual acuity alone. The experience of the examiner, the cooperation of your patient, the illumination, just to mention a few things. So many factors are concerned that I have almost come to a point where I believe we should have perhaps a new visual testing machine designed to test the low vision group that come under the definition of blindness. The ones that are on the market now are good for visual acuities that usually are above the level of 20/200 and not too good for the ones that are below that level. So we need a machine, either a new machine devised or else the present ones modified, to ensure standardization of contrast, standardization of illumination, and standardization of distance.

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[1] Project Ophthalmologist, Blinded Veterans Research Project, American Foundation for the Blind—Veterans Administration.

The question then comes up with respect to the role that muscle function should play in the definition of blindness. Should we include that as part of our criteria? The Veterans Administration, of course, has used the muscle function chart and, in cases where there is diplopia, it is most valuable in assessing visual ability or muscle function. I think that definitely should be included. There are people who have intermittent squints or problems with ocular muscle balance. When such persons are in those periods, they certainly do not see as well. Some of them oftentimes fall below the 20/200 level. This means that muscle function should definitely be included.

The problem of taking visual fields seems to give the examiners the most difficulty. The interpretation of visual fields seems to be the greatest stumbling block in our definition as we have it today. I would say that visual field taking and its plotting is a very technical job. I have always thought that this implied that there was room for almost another profession, a group of people who are highly skilled in this area. In my travels over the country I have seen great variation in the abilities of the various people that take fields and plot them. Some will use terms that mean one thing to them but nothing to anyone else. I think that we should all realize that the graduates of medical schools and the graduates of optometry schools are not a uniform product when it comes to taking vision or visual fields. They do not interpret their findings in the same manner. They are all individualists. They practice oftentimes in isolated areas, moving on from one area to another. It would be correct to assume that we should have a definition and standard set up, and not leave them room to use their own interpretation or their own judgment. I think that is one of our difficulties in our present definition—you give them an inch and they will take a mile. I think that has to be another recommendation.

I would like to make a few remarks about the technique of taking fields and the methods. There are, of course, subjective and objective methods of taking the visual field. There are over ten different ways of taking the visual field subjectively, and it is well to realize that one or two of those methods will not serve all our purposes. We have got to realize that for certain types of pathology a field will have to be taken perhaps at two meters or even farther away. There are some scotomas that, no matter how skilled you are, you will never pick up at that distance. Very often I have patients use the eye that they are complaining of and look at a theater marquee a block away to see if one letter is missing. Some scotomas are even that small. You have to use a distance that fits your vision and your pathology. In general, we can say in early macular pathology that the visual field method that we would like to mention is the Amsler chart method of taking the visual field. This is a small card usually ruled off in grid form. The patient will use it to just look at. If he sees lines that are bold or missing, parts of lines, or curved lines, it indicates an abnormality. This method will often pick up small defects in the macular area.

We are all familiar with the time-honored method of the perimeter. The normal visual field is an area that extends to 90 degrees laterally, 75 degrees down, approximately 60 degrees nasally depending upon the configuration of the nose, and 55-60 degrees upward depending upon the configuration of the eyebrows. The normal blind spot is 12-15 degrees lateral to the point of fixation. It is an area of 7½ degrees in height, 5½ degrees in width and is surrounded by a one degree amblyopic zone. Its center is 1½ mm. below the horizontal. Defects in the visual field are, of course, many. You can have hemianopsias of all types: bitemporal, binasal, homonymous, heteronymous, quadratic, etc.

Another method of taking the visual field is the confrontation method. If the examiner is unskilled it may be the most useful method of all. It is a simple method. The patient and examiner stand roughly a meter apart and it is essentially the examiner comparing the patient's field with his own, using a test object or his fingers as the test object. It does have a part in some cases in which blindness is associated with the patient being semicomatose or with some debilitating disease such that he is unable to give you the attention or the cooperation necessary for accuracy. I think that you will have to mention this as a method of taking the fields of these types of people because otherwise you simply will not be able to get anything accurate on the tangent screen, perimeter or otherwise.

Campimetry is a method of taking the central field, that refers to the area 30 degrees in radius or 60 degrees in diameter from the point of fixation. That area is mapped by either an instrument they call a campimeter or by using a tangent screen at one meter's distance. If you have a real small scotoma, you may have to use a two meter distance.

This brings up the question of the test objects. The size of test objects you use must be standardized. They must be standardized in terms of your visual acuity. A test object must be seen in order for it to be of any use. If a one millimeter test object cannot be seen, you should not use it. The way to record it is to put your test object's diameter down as your numerator and the distance as the denominator of your fraction. Most people that use a one millimeter test object for a distance of a third of a meter will want to use at least a three millimeter test object for a distance of one meter. Remember, now, we are dealing here with the laws of projection. If you project an object and form a shadow or an area with it, everytime you double the distance you double the diameter and quadruple the area involved. Remember that the ratio holds true also in test objects. Any definition you come up with for blindness should have very specifically spelled out the size of the test object in terms of vision, in terms of distance, and also in terms of color.

I find color very useful in taking fields. It has limited use, of course, but I do feel like it should not be completely shut out of the definition or in getting at your findings to come up with a definition. The various color fields vary in size, the white being the largest, of course, then blue, yellow, red, green, and violet. The red field is a very important field in neurological disease of the central nervous system. Many brain tumors will show red defects before any other color is lost. So we use red for what we call conduction defects, that is, defects that involve the bipolar cells or the optic nerve, or anything back of the optic nerve. Blue is used oftentimes to pick up nutritional defects like detached retina. Such defects will usually be picked up a little easier by blue test objects. Green is also helpful in some types of fields. I think that not only size but color of test objects should be given consideration in findings with respect to a definition.

The people on the West Coast, and in fact all over the United States, are now using a multiple test screener, developed by Harrington and Flocks. It is a rapid method for picking up a large defect in field. It is not very accurate but it has been found very useful in screening glaucoma cases, etc. It is basically a small box with a lot of lights. You press a button and find out if the individual remembers how many of them he sees at one time. There is also the after-image type of fields that are helpful but this has very limited use, however, in any definition of blindness.

Angioscotometry is a method of taking fields due to defects in the vessels of the retina and choroid. It does have a place in certain situations where there is an occlusion of vessels or perhaps isolated or localized detachments. Binocular fields are useful at times and I do not know but what that might be a good thing to consider from the standpoint of functional vision. I have always felt that the visual acuity, as taken in a doctor's office, is often at great variance with the vision that you can get by a functional method. After all, many of these people have low visual acuity, so low that the functional vision is really what is important. I think it is time now to start research work to get enough data to come up with the technique and methodology of developing standardized figures for functional vision.

There is a way of taking visual fields by flicker fusion. It is used a little bit and has a place in certain cases with large scotomas, and also in parietal lobe pathology. The normal eye can fuse a flicker into a steady light usually around 42 oscillations per second in the macular area. Further out, about 20 degrees, the normal is 50 to 55 oscillations; in the periphery the fusion ability is down to around 20 oscillations per second, as a rule. In taking visual fields, we must not forget that fixation is most important, that is fixation of the head and fixation of the eye. Most good clinics have a method of holding the chin and head steady and methods of getting adequate fixation for the eye. The methods of fixing the eye are variable. If the visual acuity is good without glasses, it ordinarily is not a problem. Usually a small white dot in the center of your tangent screen, or a small white spot on your perimeter center, or small spot of polarized light, or a small mirror will be adequate. There are many ways of doing it. Some use perimeters with a peep site. The fixation object must enlarge with a decrease in vision. The rule is that you always use the size of the fixation point to correspond with the visual acuity. In other words, you have to have something that the eye can see for it to be useful as a point of fixation. If a light is needed, use it. If you need to take a light for fixation and a light to take your field, that is a light for your test object, well, that is all right too. This also will need to be considered in a definition. In other words, the rule for fixation and test objects is the same. You use something the patient can see. One school of medicine teaches this rule in choosing a test object size. They divide the denominator of your visual acuity by the numerator and come up with the size of the test object in millimeters. For instance, if you have a visual acuity of 20/200 that would mean you would need a 10 millimeter test object for that patient to see accurately when you take the visual field. I am mentioning it because I do believe you have to correlate the size of your test object with the visual acuity. It is erroneous to think that you are going to get any standardized results by using a one millimeter test object or a ten millimeter test object on all these people with the variations in vision you find. I don't think you can do it. You won't get any field on some if you use just test objects—as a light will be needed.

Regarding the interpretation of fields, I'm not going to say a lot about it at this time because it has been very well covered. I will say that the definition we have lets people roam all over the pasture, really. Any definition you come up with should be very specific. I would not give doctors an inch, I would not let them use their own judgment at all, because you will get all sorts of interpretations. Some of them would include the fixation point in the central field, others would not. Actually, we should consider these things when we make a new definition. We should consider not the diameter of the visual field but the area. The area is the important thing, not the diameter. Then we should also consider where that visual field is; in what quardrant is it? A loss of visual field in the upper field of vision means one thing; if it is lost in the lower fields it means another. If it is lost in the temporal field it means still another. If you lose your temporal field you are going to have a harder time in mobility. If you lose your lower field you are really going to have a very hard time in walking. For instance, you cannot see the curb to step down. Remember that, in coming up with a new definition, area is the important thing. Remember that the quadrant that is affected is important. Remember that the area the test object takes up is important.

I would like to leave one or two ideas here. We must first know what we want to define in order to get any definition that can be used and would be useful to you as a yardstick. I think the people at this Conference could be a group to push the development of a new definition of blindness. I would recommend that we have one definition for blindness in the United States; and I think it ought to be called, perhaps, a definition of blindness and the severely visually handicapped rather than just blindness. If you have a definition for each of them you are going to get into trouble sooner or later by confusion. I think that the methods of taking both vision and visual fields, that is, the perimeter and tangent screen, will not cover all the pathology you will run into. I think that you are going to need several of these methods I have mentioned. You are going to have to spell out what to use and under what conditions. I think you are going to have to be very specific in your test object size and distances; and both will have to be correlated with vision.

My final remarks, then, would be to make your definition long enough and tight enough and supply it to people that take your fields and your vision. Thus, they will have data to go on so there will not be any question about any factor. Do not leave anything up to their own interpretation or their own judgment. Otherwise, you will not get a standard that will give you the results you need for model reporting. I would say at this time, too, it is time some work was done on a machine testing device for low vision and perhaps the present machines could be modified so that that can be done. I have neglected to say that, if correction is worn in taking a visual field or if you need reading glasses, then they should be worn when visual fields are taken. I think that we have to also remember that the ordinary glass lens will not always cover all the areas that you would use when you are using a perimeter, so you would have to use a tangent screen and let it go as a central field.

DISCUSSION

Mr. Stocker inquired as to whether $50.00 was an adequate fee for conducting field examinations. Dr. Lowrey was not sure what the fees were for such examinations but he thought that figure was exorbitant. He pointed out that his experience has been in a government service where well-trained technicians performed the field examinations. He emphasized the importance of experienced technicians in obtaining good results. Dr. Lowrey also stressed the need for standardization of methods. In arriving at a definition he emphasized that consideration be given to the factor of illumination. He noted that illumination may occasionally have to be different from the usual seven-foot candles. For example, certain pathology may not be detected unless a lowered illumination is used.

Mr. Friedensohn thought that from the purely statistical and medical points of view, Dr. Lowrey's proposal to tighten the definition relating to visual fields was desirable. However, he suggested that this might create a problem for the States themselves, where the basic function generally is to provide service to blind individuals. Thus, it might be of greater benefit, from the point of view of service, to use a more flexible definition so that persons in need would not be denied service because of a rigid definition. He thought this was a problem the MRA would have to face. Mr. Goldberg noted that this problem can easily be overcome, since it would be possible for the State to use a broader definition for its service program than the rigid definition which might be used by the MRA. Thus, it would merely be necessary to identify, from among this "broader" group, those who meet the rigid criteria, and only the latter would be included for MRA purposes.

APPENDIX E

Blindness Statistics in Program Planning—Library of Congress

Robert S. Bray [1]

It is obvious that the Model Reporting Area project has matured to a point where we are beginning to talk about policy in that project and to discuss attitudes and philosophy. It seems when you get close to that, and consider the Library of Congress program, you need to have full knowledge and appreciation of what reading is. A great deal of information on the reading program of the Library of Congress is contained in the available literature on that program.

As a program executive asked to comment on the place statistics play in the Talking Book Program, I would invite your attention to only one of the many aspects of administering this service program. Briefly, what I want to bring to your attention here today is the value of statistics, not only the obvious value of measuring where you have been, or of looking at any given time and measuring where you are, but most important, of measuring program goals. Anyone concerned with a program usually has, or should have, goals he wishes to achieve. I would like to say that one of my goals in the Talking Book Program is to reach at least 50 percent of our potential audience. For purposes of this discussion you have been provided with a tabulation by State which attempts to show the extent to which talking books are being used by the blind population. These are new data which we put together hurriedly to share with you. The table indicates, for each State, the number of active readers, the estimated blind population, and the percent of that population being served. The estimated blind population statistics are those made by Dr. Hurlin and published by the National Society for the Prevention of Blindness.

From these data, only five or six States have essentially reached the goal of 50 percent to which I referred. I invite your attention to Vermont which leads the nation with 65 percent of its known blind population availing itself of the reading service. And remember, this is the only general reading program in this nation. Following Vermont comes Oregon, Utah, Nebraska, Montana, and Delaware. An attempt to explain the differences among States would lead to many interesting questions, but this would be another matter.

From my position at the Library of Congress, I see the statistics of the Model Reporting Area as a very valuable tool. They would provide a means by which various States can determine how close they could come to achieving the goal of at least 50 percent of the known blind population receiving the Talking Book service of the Library of Congress.

DISCUSSION

Mr. Friedensohn asked of Mr. Bray the meaning of the difference in his figures regarding the number of active readers as compared with the number of persons who have talking book machines. Thus, for New York State there were apparently some 3,000 more machines outstanding than there were active readers according to Mr. Bray's figures. Mr. Bray commented that this excess apparently indicated that many machines were not used during the one-year report on which the statistics were based. Thus, persons who have not borrowed books within a year, although they have talking book machines, would not be included on the active reader list. The Library of Congress encouraged the librarians to find out why persons have not read books during the year. For example, when this was studied in the District of Columbia it was discovered that some of these persons recovered their sight and have returned the machines, whereas others who are still blind did not feel like reading during that period. Mr. Bray also commented that the reverse is true in some areas where there are more active readers than talking book machines, because some persons use their own record players. To this point, Mr. Mungovan added that persons, such as students, who have talking book machines use talking books and other materials which are not procured from the Library of Congress.

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[1] Chief, Division for the Blind, Library of Congress.

APPENDIX F

Blindness Statistics in Program Planning—Vocational Rehabilitation Administration

Douglas C. Mac Farland, Ph.D.[1]

The science of mathematics is at least as old as written history. In spite of its age and the important part it has played in our lives for so long a time, there were very few people, comparatively speaking, who made their living at pure mathematics. For the past quarter century data processing and its later refinements of sophisticated electronic computerization have brought the science of mathematics into practically every aspect of our lives.

Nuclear physics and the space age itself are completely dependent upon the millions of statistics received from the computers for every step along the road to the ultimate moon shot. As a matter of fact there are few large corporations which would not come to a grinding halt within a few days without the vital data fed into its managerial staff daily. One of the major measures of how well a science has become accepted is the extent to which its parlance or jargon has become a part of the normal language. Certainly statistics has become almost as popular as psychology with the average layman. There are few graduate theses, undergraduate term papers, and even high school themes today which do not attempt to use statistics in one way or another to prove or disprove the logic of their arguments, and so it is not uncommon today to read about the chi-square formula, application of the t-test, and the use of correlation techniques. These are but a few of the less sophisticated terms which we read daily if we are even remotely connected with education. Students use these and much more refined techniques to lend credence to their writings, and it would not surprise me at all to find them liberally applied in our popular magazines in the coming years.

It is not my intent in the short time allotted to me during this panel discussion to give you a history or defend the science of mathematics. There are many more knowledgeable people who can handle this subject much better than I can. Nor is my purpose to discuss with you the various abuses that mathematics, and specifically its branch of statistics, have been subjected to during the past decades. I began my discourse in this manner only to highlight one staggering fact which should be appalling to everyone who is a professional worker in our field. In spite of our long history of work for the blind, which began in this country over a hundred years ago, we still do not have any exact information regarding the number of blind persons in the country nor the reasons for their blindness.

All of our calculations today about the blind population of the United States are based on the prevalence studies of Dr. Ralph G. Hurlin. Great credit should be given to him for the valuable work he has done during the past twelve years but doesn't it seem rather inexcusable in this day of advanced physical and social sciences that we are unable to provide exact data on such a small number in our total population. One might ask, with the prevalence of blindness statistics which we have available, the number of studies which have been conducted with regard to specific eye diseases, what more is really needed to do a good job in this field?

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[1] Chief, Division of Services for the Blind, Vocational Rehabilitation Administration, Department of Health, Education, and Welfare.

Let me explain the situation as we see it from the standpoint of the Vocational Rehabilitation Administration. Currently we have in Congress legislation which if enacted into law will have far-reaching effects on the disabled and specifically the multidisability groups of our Nation. The new law will provide a great impetus to our State-Federal partnership in constructing and staffing workshops for those who are unable to engage in outside competitive employment. We will be in a good position to build, equip, and operate work opportunity centers for the development of the skills of the multiply handicapped who will eventually become production workers in sheltered workshops, or, more hopefully, might progress to outside competitive employment.

Our Division of Services to the Blind has just completed a long-range plan for the most efficient use of these workshops and work opportunity centers for the blind. In addition, the law will permit us to engage in constructing and staffing comprehensive rehabilitation centers for the blind. At present we have approximately 22 such centers with a capacity for serving 1,000 individuals per year. Based on Dr. Hurlin's calculations, we are planning to double the number of rehabilitation centers within the next ten years. The centers will be of a more comprehensive nature and will be able to serve more clientele. It is, therefore, estimated that by 1975 we should be able to serve at least 3,000. The law encompasses intensive training periods for the multiple handicapped blind person as well as Federal matching funds for management services to our vending stand program. In fact, the legislation is geared to help us serve those who would have been considered infeasible under the old act. As soon as the new provisions become operable, there is no reason why we cannot hope to double the number of rehabilitations within the next five years and increase them proportionately in the coming decades.

Although it is not impossible to plan intelligently on the basis of statistics we now have, it would be so much more helpful if we know exactly how many blind persons there are to be served and the extent of their disability, their current age, age at onset of blindness, cause of blindness, and other handicapping conditions present, along with an analysis of which blinding conditions are increasing in certain age groups. Let me illustrate. We have noticed a vast increase in the number of persons who have diabetes who are now requesting services at our comprehensive rehabilitation centers. The studies we have available tell us that approximately 11 percent of blindness is caused by diabetes, and yet most centers report that at least one-third of the total clientele served by them are individuals who have been blinded by diabetic retinopathy. Exact calculations obviously would be very helpful in the future planning of our centers. The whole picture of physical restoration as we know it in practice in our rehabilitation services would be vastly improved if we had registries around the country similar to those being propounded here today.

Certainly, it is not my intent to take the entire afternoon discussing our plans for rehabilitation but merely to show you what registries could mean in each State and what interchangeable registries can mean nationally. For example, we have approximately 25 optical aids centers. We are planning to open 40 of these centers during the next ten years. From experience we know that the new centers will have to serve more people. At present most of the centers operate one day a week, some less. We recognize that with the scarcity of ophthalmological talent this is wasteful. It is our plan to combine these with other facilities where the total practice of physical restoration can be carried on.

Expansion of training facilities is vital if we are to meet the professional needs of the future. Two areas in which this need is demonstrated are home teaching and mobility instruction. Figuring very conservatively, there are many thousands of blind persons who need a modicum of travel training. Obviously, this need cannot be filled by the number of graduates being turned out from the two schools now in operation. Neither can the need for home teachers be met by one graduate school.

We have been giving a great deal of thought to the development of programs which will take advantage of future opportunities available to the blind and for phasing out of those job operations which we have depended upon since the close of the War. All of our calculations and plans, however, at the moment must be based on educated guesses. I cannot emphasize too strongly how vital it will be for us and for others working in our field to have exact statistics on which we can base what we do and whom we will serve.

I have been very interested in listening to the several reports given this afternoon, especially the report by Dr. Goldstein covering the studies which are now being conducted in the Middle East, particularly in Egypt. I cannot, however, view this without some feeling of frustration in view of the sense of urgency which we now feel in our planning for large programs to serve blind citizens of our own country. I am, of course, impressed and encouraged by the fact that 17 States now have or are about to have completed blind registries and that four or five States are currently developing a plan which will lead to entry into the Model Reporting Area. The unanswerable question, to me, is why many more States have not taken advantage of the technical help offered by the National Institute of Neurological Diseases and Blindness and the financial assistance they will provide for initial staffing.

I have been privileged to meet with this group, first as a State Director and now as Chief of the Division of Services to the Blind, for the past three years. It is my fervent hope that three years from today I will be invited to meet with the group once again, but at that time we will have full representation from all States and territories of our Nation and that information will be so recorded that if one wishes to know the number of cataract cases in the country, those suffering from diabetic retinopathy, the age distribution, or any other vital statistic which is so necessary to us to serve blind clientele, it can be provided within a matter of hours.

APPENDIX G

Blindness Statistics in Program Planning—Welfare Administration

Robert H. Mugge, Ph.D.[1]

I cannot conceive of an intelligent person operating a store without keeping an inventory of the goods, keeping this up to date, finding out what goods are selling, what goods are not being sold, how many customers are coming into his store, and what they are interested in. I cannot conceive of an intelligent manufacturer that didn't keep an eye on which of the materials he is producing are selling and which are not. I cannot conceive of an intelligent airplane pilot operating one of our modern planes with a complex instrument panel but flying in the old method by the seat of his pants. Yet it appears to me that the administrators, the boards, the legislators that in effect operate our very expensive, very involved, very important public programs for the blind in many cases around the country are doing just this. They are operating these programs largely without the facts they need, and, in too many instances, they are not seeking the facts.

We are trying to overcome this problem in our own agency and to help the States overcome the problem of ignorance in relation to the various public assistance programs partly through our Research Division in the Bureau of Family Services. Mr. Garnett Lester directs one of the research groups in this Division, the Medical Care Research Group, and I am responsible for a group called the Demographic Research Group. We primarily conduct surveys on the case loads of our programs.

In 1962, we finally got around to conducting a national survey of recipients of Aid to the Blind. Some of you who have been associated with earlier studies of Aid to the Blind might blanch at this particular statement because studies of the program have been made before, notably the very well-known study of causes of blindness made in the early forties. But, unfortunately, that was not really a nationwide study. It was a voluntary study and only 20 States participated. It was also not very extensive in its content, limited mainly to causes of blindness and needs for services. In 1950 or 1951 a special study was made of employed Aid to the Blind recipients, but that was quite limited too. It was not really until 1962, when Aid to the Blind was 27 years old, that a really nationwide survey of this population was conducted. We had many difficulties, as one usually does in this kind of operation. We are still getting out the results of this survey, and we hope those of you who are involved in Aid to the Blind in one way or another, or are particularly interested, have somehow or other received the publications that have come out of it. One was a quickie publication that was done showing the national findings, followed by a set of tables showing data for all the States. Incidentally, all of the States, with the exception of Guam, participated in this study, which is quite unusual even for our required studies. Guam was excused because it has only about a dozen recipients.

We publish annually program facts which give the principal population data on our programs and includes a section on Aid to the Blind. Although our Aid to the Blind survey data fall into the general category of this session, namely, blindness statistics, to us it is one of five programs. And it probably receives less attention than any other program, partly because it is by far the smallest public assistance program, and perhaps partly because it has the fewest problems. We have some 7,200,000 recipients in our five Federally-aided assistance programs. Of this 7,200,000 there are fewer than 90,000 recipients of Aid to the Blind, and some ten to fifteen thousand of these are recipients in Pennsylvania and California not eligible for Federal participation.

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[1] Chief, Demographic Research Group, Division of Program Statistics and Analysis, Bureau of Family Services, Welfare Administration, Department of Health, Education, and Welfare.

In last month's issue of "Welfare in Review," we have a general report on the findings of the 1962 survey. I would like to go through very quickly with you the substance of this report to try to give you some idea of the program value of these kinds of statistics. To start with, the survey of Aid to the Blind was extensive in character rather than intensive. It was intended to secure population type information that could be obtained through case records fairly simply and cheaply. Case workers know their cases. These workers make involved inquiries in the process of reviewing eligibility for public assistance. Therefore, the case records contain a great deal of information on the individual recipient. The case worker could not, of course, work with the recipient without information of this kind. But, unfortunately, this kind of information usually lies there, in the case record and in the case worker's mind. It seldom goes beyond that point. If it did, it would enable the directors, the boards, to find out about these recipients so they would know how better to administer the program for these recipients in the circumstances in which they are found.

This survey was intended not to ask piercing questions of these recipients, but rather to obtain the fairly simple quantitative, objective kinds of information that were known but had not been tabulated. Each State collected the prescribed data for a sizable sample of their recipients so that we were able to compile not only national data but, for much of the information, comparable State data. The kinds of information obtained were these: "What is the place of residence? Are these people concentrated in the cities, in the small towns, in rural areas? What parts of the country do they tend to be concentrated in? What are their ages?" As Dr. Mac Farland mentioned earlier, this is of primary consideration because it alone tells you so much. It tells you a great deal about the capabilities of these people, whether it makes much sense to set up a big employment program for them, etc. Race and sex distribution, of course, is very relevant to the services. What is their marital status? How many children do they have? Are they still responsible for minor children in the home? What are their living circumstances? How many of them are living alone? How many in institutions? How many with other relatives? What is their education? This by itself, of course, does not tell you everything about them, but it gives you some important leads as to the kinds of services they can well utilize, the kinds of educational and recreational programs that might be of value to them, the kinds of special facilities that may be needed. I trust you will be interested in looking at our figures on what the States report regarding the extent of use of the talking books. We secured information on that and the results are very interesting. How many of them can read braille? How many of them have guide dogs? What is the current level of employment of the men and women in the program? This is relevant to all of the political action relative to disregarding income of the Aid to the Blind recipients. How long do they receive assistance, once they get on to the program? Are they natives of the States in which they live or are they migrants, and if migrants, how long were they here before they started receiving assistance? Such questions are important to relation on residence. Are people moving into a State to get into a more generous assistance program? To what extent does Aid to the Blind overlap with other programs in the household? Are other family members receiving other kinds of assistance? Is this a generally needy family, or is just one individual in the family in need? What kinds of services the recipients have been receiving from the agency, of course, is of special interest in planning our service program. Visual and other health conditions were looked into. I should say, in this connection, that Ralph Hurlin, Elizabeth Hatfield, and others gave us great help in this. We, unfortunately, were not able to wait with the survey until the new cause of blindness classification finally came out, but they let us have it as it was at that point. I am sure it was a great improvement over the former code. The causes of blindness, as reported by the ophthalmologist, were coded with the help of the State supervising ophthalmologist. We have the distribution of cases according to the site and type of eye affection, the etiology of the blindness, and the degree of blindness. Of special interest is the age at which the recipients lost their sight. Obviously the younger recipients had to be fairly young when they lost their sight, but when was sight lost by the older recipients who had been at risk of losing their sight through a longer lifetime? Did they live most of their lives with or without their sight? What other physical impairments were reported on these recipients? What chronic physical or mental conditions? What about their mobility and travel arrangements? How many are confined to the home, bedfast, chairfast? How many of them can get around alone? Reprints of this particular report are being printed and will be available soon. We can make a supply of these available for distribution to this group if it is desired.

In addition, we have a great deal of financial information that is not reported in this particular article. It will be reported on in a special article when we can show how much is earned by the recipients with earnings, how much of this income is disregarded now under the law, and how much is applied toward the State recognized requirements. Their financial needs, their incomes, and the level of unmet needs under their State plans will be reported on, as well as the degree to which Social Security meets their needs.

This 1962 survey really, for the first time, gives us the big picture for the Aid to the Blind recipients for the nation as a whole and for the State programs separately. We know a great deal more in order to answer the legislators' questions. We know a great deal more to combat the misinformation that we find in the newspapers every day. This seems a hopeless task, but we keep working at it.

DISCUSSION

Mr. Friedensohn wondered whether there was any way in which Dr. Mugge's studies on characteristics of people on public assistance can make it possible to determine how many blind persons there are on such programs as Old Age Assistance and Aid to the Blind. This kind of information would be of value in the 20-year program plan which Mr. Friedensohn will have to prepare for his State. Dr. Mugge stated that this kind of information was included in a 1953 study of Old Age Assistance, and although it was not included in the 1960 study, it will again be included in the study being made this year. Thus, data of this kind can be obtained through such studies. Based on the 1953 data, there apparently were more aged blind receiving Old Age Assistance than were receiving Aid to the Blind.

Mr. Goldberg inquired as to how programs such as Old Age Assistance can determine which of its recipients are blind since an ophthalmological examination is not normally conducted as an eligibility requirement. He pointed out that this kind of information would be extremely valuable to the agency maintaining the register, since this may be the only means by which the agency maintaining the blind register could learn that the particular individual was blind. Since these are older people the loss of this information may have a material effect on the statistics relating to the age distribution among the reported blind population. Dr. Mugge commented that this determination of whether or not an Old Age

Assistance recipient was blind was in most cases not based upon an ophthalmological examination, but rather based upon the report of a case worker's observation of the recipient. In the current study recipients are asked to report by mail questionnaire on various defects and conditions, including blindness, which they may have. Thus, this kind of data would be only a rough measure and would be obviously limited in value.

Mr. Stocker stated that in Oregon they have found two ways that this problem could be overcome to some extent. One way concerns the Medical Assistance for the Aged Department. If case workers put blind persons on blind assistance until they can get the medical services taken care of, this enables the blind register to learn of their visual defects. It is only a matter of a bookkeeping transfer thereafter to put persons on the Old Age Assistance program. The other method is to increase the blind assistance to a point where it is greater than that under Old Age Assistance. Thus, blind persons would tend to come under the Aid to the Blind program and thereby come to the attention of the register. Dr. Mugge stated that the difference in receipts according to type of program varies among the States, some States giving greater assistance under Aid to the Blind programs and other States giving greater aid under the Old Age Assistance program.

APPENDIX H

Blindness Statistics in Programs Planning—Oregon Commission for the Blind

Clifford A. Stocker[1]

In these days of project planning and program development to improve services for the blind population of this nation, it becomes increasingly more important to have reliable blindness statistics available. Such statistics can only be derived from equally reliable data and such data must be taken from a set of carefully compiled and meticulously maintained records. This sort of a set of records naturally results in a refinement and standardization of certain information about blindness so that it will demonstrate a commonality of factual evidence about blindness throughout the country. Hence, if there is to be any efficient nationally coordinated project planning and program development of services to the blind population of the nation, dependable blindness statistics are an essential preliminary ingredient of such a universal set of activities. It, therefore, becomes the responsibility of each State to develop the best set of blindness statistics possible. The MRA plan is at least one way this can be accomplished. The uses of such statistics are many and varied, both on a national level and on a State and local level.

In Oregon we have just nicely gotten into the maintenance of an adequate register with its various sets of data. From these data we shall be able to develop some significant statistical inferences and we have already found many uses for these blindness statistics.

Our uses of blindness statistics seem to be in answering inquiries directed to us about the extent and causes of blindness and what can be done about it. Such inquiries may come from a volunteer service group, medically oriented organizations (e.g., public health agencies and medical schools), professional social work agencies, schools and colleges, legislators and legislative committees, newspapers and other media of public information and a host of other inquirers. Some rather classical instances of how the data developed by the Commission were used advantageously by other State and local agencies are:

1. The State Motor Vehicle Department, in its drivers licensing program, has established certain criteria with regard to visual impairment of applicants for and holders of driver's licenses in Oregon. During this session of the Legislature several bills were introduced relative to these criteria. In justifying these bills the charge was made by at least two legislators that "dozens" of the State's duly licensed drivers were legally blind. The Motor Vehicle Department asked the Commission to help it check out the facts in hope that these charges could be refuted. The Commission arranged with the data processing section of the State Board of Health, from which the Commission purchases its data processing work, to send the Motor Vehicle Department a copy of the list of names and addresses of persons on the Commission's Register of the Blind. Further arrangements were also made to send the Motor Vehicle Department a copy of the list of names and addresses of each month's additions to

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[1] Administrator, Oregon Commission for the Blind.

and removals from the Register. The Motor Vehicle Department is thereby able to keep its list current and may check it against their list of holders of valid driver's licenses and new applicants each month. When the Motor Vehicle Department finds the name of a holder of a valid driver's license on the Register of the Blind they ask said driver to report for a current visual examination. If the holder of the license or the applicant is found to be blind he must surrender the driver's license, and if he is found not to be legally blind but still having a severe visual impairment the examination results are referred to the State Board of Health for ruling on the type and extent of restrictions to be imposed on the licensee. In both instances the Commission is kept informed regarding the client, and results of the examination are made available so that the Commission may take the proper action relative to its Register. The Board of Health comes into the picture because it is the statutorily authorized agency in the State responsible for reviewing medical examination reports on all applicants for special or restricted driver's licenses, be they orthopedically, emotionally, mentally, otologically or visually impaired. It is upon their decision that the Motor Vehicle Department issues or denies any special or restricted license. Because of its role in this particular matter of State business, the State Board of Health, Motor Vehicle License Section also gets a copy of the Commission's Register list and copies of the regular monthly additions and removals. A most important by-product of the Commission's work is that of making known to these two cooperating Departments those who have a visual limitation but are not legally blind. It is anticipated the number of these cases will be sufficiently great during the next two years as to warrant special legislation for services to them. It is not at all unexpected that the Commission may have to start some programs to serve this group. The Commission already has the statutory authority to do so but has, because of budgetary restrictions, kept its services pretty well confined to legally qualified blind persons.

2. The second "for instance" is the use of blindness statistics made by Public Welfare both on a State and a local level. The number of Old Age Assistance recipients who are blind can readily be determined by comparing our list with their list of persons in this category of public assistance. The same process of comparison may also be used for all other categories of public assistance. It is quite possible that the welfare agencies may also know of legally qualified blind persons whose names do not appear on the Commission's Register, thereby helping the Commission to bring the Register up to a greater degree of accuracy. All of these comparison checks have budgetary implications and are used in planning various services.
3. Last, but far from least, are the significant uses to which the Commission has been able to put these blindness statistics. In considering plans for the 1965-67 biennium reference has frequently been made to the constituency of the blind population of the State and selected areas therein. By closely examining the Register, the sorts of services which the Commission should emphasize or build around for the forthcoming years may better be determined. The need of funds for case services, personnel needs, industrial development, all have a sounder basis if they are founded on the statistical evidence available from the Register. As additional years go by and the data for these years can be collected the accuracy of blindness statistics will be improved. In fact, it should become possible to enter the area of probability in prediction of services and activities to be provided in long range planning.

> There is little doubt about the value of developing and maintaining a reliable set of blindness statistics. There is even less doubt about the amount of work involved in compiling and maintaining the data essential to the development of these statistical inferences. Finally, there is no doubt but that the former justifies the latter.

DISCUSSION

Mr. Mungovan stated that there probably was no great general acceptance among States as to the uses to which their registers were put, particularly with regard to turning lists of registrants over to other agencies for any purpose whatever. He stated that in Massachusetts they have had to attack this problem of providing information to the Motor Vehicle Department on the constitutional grounds that this was an invasion of privacy. He stated that the only persons in this country who are registered with the government because of a particular physical defect are blind persons. Consequently, their rights should be protected, and information regarding such individuals should be made available in the same manner as for other persons with physical handicaps. Mr. Mungovan said the question of turning over lists for purposes such as the Registry of Motor Vehicles was a serious problem in many quarters.

Mr. Friedensohn stated that the reverse situation was true in New York State. The New York State Commission for the Blind has been in contact with that State's Bureau of Motor Vehicles and initially conducted a check of all 30,000 names of blind registrants against the Bureau of Motor Vehicles' records. This checking procedure is now done semi-annually on the new additions to the register. Mr. Friedensohn stated that as a by-product of this activity, the Commission learns about persons on the register who are no longer blind because of restoration of vision through medical treatment, removal of cataracts, etc. This information is given to the Commission by the Motor Vehicles Bureau after it has obtained examinations on persons registered with the Commission. Thus, the referral back to the Commission of results of the examinations helps keep the register up to date and current. Such information might not have been available in any other way. In commenting on the implications of providing lists of blind persons to the Motor Vehicle Registry, considerations come to light from a constitutional point of view, such as whether the holding of an operator's license is a right or a privilege. The Commission felt very strongly that blind persons who can cause tremendous property damage or danger to other persons' lives should not hold driver's licenses. The rationale here would be that the holding of a driver's license would be a privilege rather than a right.

Mr. Mungovan said that several years ago he had discussed this matter with the President of the American Medical Association which was and still is concerned with this problem. He mentioned that the President did agree, in part, with Mr. Mungovan's point of view after they discussed the various reasons why the register should be kept confidential. Mr. Mungovan stated that there are only a very small proportion of blind persons who are drivers in contrast to thousands of persons licensed to drive automobiles who perhaps should not be. Yet the latter persons are not registered and, hence, are dealt with differently from blind persons.

Mr. McCollam said that in Connecticut they have taken a little different approach to this problem. According to their policy, when they find a blind person holds an operator's license and is continuing to drive, a staff member of his agency advises that person that if he continues to drive, the agency will be obliged to report that fact to the Motor Vehicles Commissioner. Thus, they advise a blind person to give up driving voluntarily and turn in his license before any action is taken to report the individual to the Department of Motor Vehicles. This seems to have worked out rather satisfactorily. In most cases the blind person is willing to yield to this, although some of them do it rather regretfully.

Mr. Mungovan stated that for certain of the blind people, there was no question or problem regarding the turning over of information to Motor Vehicles. On the other hand, the question, however, was one of turning over the entire list of registrants. He indicated, for example, that a blind person was denied services because he was driving a car while on the blind register, having had a waiver from the Registry of Motor Vehicles Committee to drive an automobile.

Miss Ford stated that a number of persons who are receiving Aid to the Blind wear contact lenses although they state that they cannot do so on a full-time basis. However, when they obtain their driver's license, they use the contact lenses enabling them to see satisfactorily for such periods of time that they are able to wear the lenses.

Mr. Friedensohn commented on the relationship of this issue with regard to program planning. He pointed out that his Commission was now working with the Commissioner of Motor Vehicles on amending the State's physical requirements for holding driver's license in New York. This is a complex process being tested out to validate to the Legislature the effect of vision impairment in relation to accidents, and this whole process came about through the sharing of the blind register list with the Registry of Motor Vehicles. Apparently, there is no common standard among any of the 50 States with regard to visual loss in holders of driver's licenses. In New York State they are attempting to have written into the law the inclusion of testing of field limitation in terms of vision standards for driving. He indicated that now there is a re-examination at least every nine years for all persons over 40 years of age regarding suitability for holding of driver's license and stated that, hopefully, the legislature may reduce this interval to six or even three years. Mr. Mungovan indicated that there was proposed legislation in his State for five-year periodic examinations and that this would be a very satisfactory solution.

APPENDIX I

Blindness Statistics in Program Planning
Vermont Department of Social Welfare

Virginia Cole[1]

I am sure that we in Vermont have no corner on the use of blindness statistics in program planning. It would seem impossible that anyone should have gone through the efforts of gathering this statistical data about people without correlating it with the activities aimed to serve these same people. It was very noticeable to me that in the morning reports it was nearly impossible to talk about registers without relating them to programs. It seems equally impossible that any one agency would have thought of *all* of the uses to which the data might be put. Considering also that no two agencies for the blind are identical, I would like to present my part of this symposium as a sort of questioning—a searching — a provocation — for further thought and discussion. I will not profess to have the answers.

We—and I mean all here at this gathering—are, or should be, constantly asking "What have we accomplished, what are we doing, and what are we planning for the future?" I sometimes wonder how we *ourselves* can ever find an honest answer to the first two questions because of the innate tendency of every human being to have some sort of vested interest. But the third question—"What are we planning for the future?"—can be considered very honestly if we acknowledge the vested interests and then turn to the honest figures which are coming from our efforts in MRA.

Let us acknowledge, then, that there *is* a distinction between getting and keeping the data, versus *using* it to develop programs to serve people with problems.

Back in 1956 (which seems so long ago!) in a talk to the New England Council, the President of the National Life Insurance Company, Deane C. Davis, said, "One of the things we truly lack in Vermont is needed statistics of validity and content sufficient to tell ourselves about ourselves in a way that will be meaningful and helpful."

It seems to me that we now do have—with the help of NINDB—those needed valid statistics which tell us about people with vision problems and their needs.

First, what are their ages? What proportion of the total blind population are preschoolers, are of school age, are in the young employment class, are in the older employment age group, and finally are in the senior citizen age group? What are the needs of each of these age levels and how do we plan for their education, their rehabilitation, their adjustment to their loss of sight?

Then let us take a look at their sex. In this matriarchal society I cling to the old notion that there *is* still a difference between the sexes and their life goals. Do we need to place more emphasis on developing facilities for rehabilitating homemakers because of the apparent higher incidence of blindness among women?

Next, what do we observe from the data on etiology? What percentage of those registered have debilitating diseases and are concerned with special health problems as well as sight problems? How many are diabetic, brain damaged, tubercular, hard of hearing, retarded, mentally ill, epileptic? And does this point up the need to develop closer working relationship with health agencies interested in glaucoma detection, diabetes detection? How many have operable cataracts? How many glaucoma patients should be followed in the interests of preventing further vision loss?

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[1] Director, Division of Services for the Blind, Vermont Department of Social Welfare.

A look at degree of vision will guide us in determining how many might be helped through optical aids. Should we develop more low vision clinics?

Our register includes type of residence. How many are homebound—not able to compete in the ordinary labor market but still capable and wanting desperately to work their own way? Should we develop employment programs for the homebound? Or expand workshops serving the multi-handicapped? How many are in nursing homes or homes for old folks? Do we need to step up recreation therapy to serve these people? Would they benefit through developing a volunteer friendly visiting program? Do they need to be taught a modicum of mobility? Do all who can make use of them have talking book machines?

What percentage of referrals emanate from the primary source—the ophthalmologists? Do we need closer contact with these physicians toward more efficient referral systems?

These are all familiar questions to all of us. We have thought about them often, but have we had up to now the valid figures which over a period of years will point up trends and enlighten us as to where the need is greatest? We have learned that we cannot cure all the ills of the world. There just is not money enough. And so we must prepare budgets and present them to legislators. If we can show trends and changes with valid attention-getting figures instead of surmises or intuitive assertions, we will gain favorable public opinion for support of the service needs as we have analyzed them in accordance with their importance. We need to know what kind of *training* to plan for our staffs, and to know what kind of research we want to support or to implement.

Blind persons, relatively speaking, are few in number and widely scattered—in Vermont we say "around the sap-works," and so the *total* problem is not seen by the general public. Concrete statistical figures used in news releases, pamphlets and annual reports —when given in small doses and emphasizing some one particular point—will help to win the much needed support from the legislators and the public. And what a wonderful feeling to have those figures backed up by the National Institute of Neurological Disease and Blindness.

I have alluded to coordination with other agencies and would like to mention several examples of this interaction in Vermont.

1. The State Department of Health is requesting money from the legislature for a program of immunization against measles. They asked our agency for the number of persons registered as blind due to measles and what it cost to educate and rehabilitate them. We were able to give them this information but could not have done so before the era of MRA.

2. A Dartmouth College intern wrote of his interest in the hereditary pattern underlying congenital anophthalmia. We did find *one* on our register and sent him the information he requested. We would not want to discourage him in this interest, but how much more intense our desire to support diabetes prevention!

3. The Executive Secretary of the Governor's Committee for the Aged was planning an extensive exhibit for the legislators. He wanted to spot in towns on a large map all blind persons over 65. We were able to give to him the number in each town and county. The exhibit is getting considerable attention this week at the State House.

4. The Division Staff, feeling the need to know more about the problems of the diabetic, arranged a seminar with doctors from the Health Department and Medical College and invited other social workers in the area to attend.

It appears in these few examples that "Fraternity of Purpose" (a phrase used by M. Robert Barnett) is at work here. We hope so. We owe special thanks to NINDB for the fraternity of purpose displayed here today toward making the lives of blind persons more enriched and ultimately to reduce their numbers.

May I repeat my hope that these very brief remarks will provoke much further discussion about using blindness statistics in program planning.

APPENDIX J

LIST OF PARTICIPANTS

FOURTH ANNUAL CONFERENCE

Model Reporting Area for Blindness Statistics
May 20-21, 1965

State Agencies

Model Reporting Area States

Connecticut Board of Education and Services for the Blind
- Matthew R. DeMartino, Chief, Adult Services
- H. Kenneth McCollam, Director

Kansas Department of Social Welfare
- Harry E. Hayes, Director, Services for the Blind

Louisiana Department of Public Welfare
- Miss Evalena F. Ford, Medical Social Consultant for Eye Services

Massachusetts Department of Education
- John F. Mungovan, Director, Division of the Blind

New Hampshire Department of Health and Welfare
- Carl Camp, Supervisor, Services to the Blind

New Jersey Department of Institutions and Agencies
- Joseph Kohn, Executive Director, Commission for the Blind

New Mexico Department of Public Welfare
- Harold J. Hebbeln, Supervisor, Division of Services for the Blind

North Carolina Commission for the Blind
- Miss Christine Anderson, Supervisor, Social Service Division
- Mrs. Marie Norris, Registrar

Oregon Commission for the Blind
- Clifford A. Stocker, Administrator

Rhode Island Department of Social Welfare
- Miss Eva M. DeTommaso, Chief Clerk, Division of Services for the Blind

Vermont Department of Social Welfare
- Miss Virginia Cole, Director, Division of Services for the Blind

Virginia Commission for the Visually Handicapped
- William T. Coppage, Director
- Mrs. Rose Minter, Executive Assistant

Non-Model Reporting Area States

District of Columbia, Department of Vocational Rehabilitation
- Stephen A. Gambaro, Chief, Division of Services to the Visually Impaired
- Thomas M. Leatherwood, Registrar, Division of Services to the Visually Impaired

Georgia Department of Education
- W. B. Gaines, Supervisor, Services for the Blind, Division of Vocational Rehabilitation

Maryland Department of Education
- Hugh Bunnell, Rehabilitation Counselor, Division of Vocational Rehabilitation
- George W. Keller, Coordinator, Services for the Blind, Division of Vocational Rehabilitation

New York State Department of Social Welfare
- Oscar Friedensohn Director, Commission for the Blind
- Mrs. Cathleen F. Lawlor, Supervising Consultant on Eye Health, Commission for the Blind

South Dakota Services to the Blind and Visually Handicapped
- Mrs. Helen Flora, Fiscal Officer

Utah Department of Public Instruction
- Dr. Vaughn L. Hall, Administrator, Division of Rehabilitation

National Voluntary Agencies

American Foundation for the Blind, Inc.
- Dr. Milton D. Graham, Director, Department of Research
- Dr. Austin Lowrey, Jr., Project Ophthalmologist, Blinded Veterans Research Project
- Richard E. Onken, Research Assistant, Department of Research
- Robert L. Robinson, Research Director, Blinded Veterans Research Project
- Mrs. Marie M. Sarchin, Medical Record Librarian, Blinded Veterans Research Project

National Society for the Prevention of Blindness, Inc.
- Mrs. Elizabeth M. Hatfield, Consultant in Statistics

Private Agencies

American Institute for Research
- Dr. Victor Small, Acting Program Director

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